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ABSTRACT

The report examines implications of applying a functional rather than categorical definition of disabilities to Connecticut's services for the developmentally disabled. Specific objectives included preparation of an overview of services available, an analysis of policy options and system constraints, an analysis of the implications of reorganizing services, and a discussion of implementation phases. The first section of the report lists project goals and project methods and products. The second section describes a policy framework underlying the project's general approach to policy development. The following section describes the project context including trends at the federal level, the historical background of the service system in Connecticut, the extent of the current service system and the strengths and weaknesses of programs for persons with disabilities. The next section describes the experience of other states (New Jersey, Ohio, Maryland, Hawaii, California) that have reorganized their services along more functional lines. The final section presents the principles that should govern the service system, the outlines of recommended changes, the implications of such changes regarding demand and cost, and the ramifications for service eligibility procedures. This concluding section also discusses implementation phases. An appendix contains instruments used to screen adult applicants to the Division of Developmental Disabilities. (DB)

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Human Services Research Institute

ED300950

THE FEASIBILITY OF ADOPTING A FUNCTIONAL DEFINITION OF DISABILITIES:

A POLICY ANALYSIS AND RECOMMENDATIONS

Prepared for:

Connecticut Planning Council on Developmental Disabilities

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January 30, 1988

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APPENDIX A: SCREENING INSTRUMENTS

I. OVERVIEW

A. Project Goals

During the past several years, distinctions among the needs of persons with various types of physical and mental disabilities have become less numerous as more general notions of normalization, community integration, independent living, and multiple forms of environmental adaptation have gained currency across the disability community. These trends have been coupled with an increasing desire in the field of developmental disabilities to move away from categorical eligibility criteria and service organizations to a more functional approach to the provision of services. In other words, systems of services should be based on the ability of individuals to function in a range of life spheres rather than requiring specific labels to secure entry into the system.

In response to these emerging aspirations and a perception that the current service system in the state was fragmented and inefficient, the Connecticut Planning Council on Developmental Disabilities contracted with the Human Services Research Institute to assess the feasibility of setting up a state department of developmental disabilities. The specific objectives of the project involve the preparation of an overview of services available, an analysis of policy options and system constraints with respect to organizing services for persons with disabilities, an analysis of the implications of reorganizing services, and a discussion of implementation phases.

This concern with a more functional approach to the organization of services is mirrored at the federal level where the new amendments to the Developmental Disabilities Act require state developmental disabilities programs to assess their current activities to determine whether they in fact are directed at the range of individuals covered by the definition of developmental disabilities. The new law will be discussed in Section III.

B. Project Methods and Products

The study provided an opportunity for members of the Council, state agencies providing services to persons with disabilities, and advocates to review relevant data and explore policy options regarding the optimal way to organize services in the State of Connecticut. To do this, project staff collected descriptive and quantitative data to facilitate the following outcomes: 1) improve the coordination and responsiveness of services to persons with disabilities; 2) fill gaps in the current service system; and 3) deliver services to individuals whose needs are not currently being fully addressed.

During phase one of the project, staff conducted two public forums -- one for providers of services and one for consumers of services; a review of major policy documents including budget proposals, legislative reviews, program descriptions, and other consultant reports; and numerous interviews with individuals around the state who provide services, manage services, fund services, advocate for services and receive services. These activities led to the preparation of an initial policy paper "mapping" the current system and presenting an overview of its strengths and weaknesses. Following the circulation of the paper, a meeting of the "Sounding Board" committee was held to review the initial findings. This committee was made up of representatives of the relevant state agencies and advocacy groups with interests in services to persons with disabilities.

The purpose of the second project phase was to review how other states grappled with similar policy changes. Specifically, staff reviewed written reports on the impact of changes in the definition on eligibility for services, and contacted representatives in states that made reforms in their service systems similar to those being considered in Connecticut. The purpose of the first activity was to understand how the magnitude of the target population is likely to change given changes in the definition of service eligibility. The purpose of the second activity was to secure direct feedback from those involved in system changes on the course of implementation.

The subsequent policy paper included a discussion of the impact of definitional changes, a review of the experience in five states, and a discussion of the implications of other states' experiences for Connecticut. Following the circulation of this policy paper, another meeting of the "Sounding Board" committee was held and the contents reviewed.

In the third project phase, concrete proposals for reorganization of the service system for people with disabilities were circulated and estimates were generated to reflect the potential increased demand of such changes. Two additional "Sounding Board" meetings were held to review and refine the proposals. Legislative testimony regarding project activities was prepared and presented in December.

The final project task was the development of the ensuing report which summarizes all the data collection and analysis activities and presents HSRI's final recommendations and cost estimates.

C. Organization of the Report

This final report has four additional sections. The next section describes a policy framework which will help the reader to understand HSRI's general approach to policy development. The following section describes the project context including trends at the federal level, the historical background of the service system in Connecticut, the extent of the current service system and the strengths and weaknesses of programs for persons with disabilities. The next section describes the experience of other states that have reorganized their services along more functional lines. The final section presents the principles that should govern the service system, the outlines of recommended changes, the implications of such changes insofar as demand and cost, and the ramifications for service eligibility procedures. This concluding section also includes implementation phases.

II. POLICY FRAMEWORK

A. Policy Logic

Before describing the results of the policy analysis, it is important to discuss the general policy development framework that guided project staff. This conceptual approach, which was originally designed by Larry Lewin (Lewin and Associates, Washington, DC), stresses the importance of beginning any analysis with an accurate description of the phenomenon or "world" under study. Thus the first canon of this policy logic is **DESCRIBE THE WORLD ACCURATELY.**

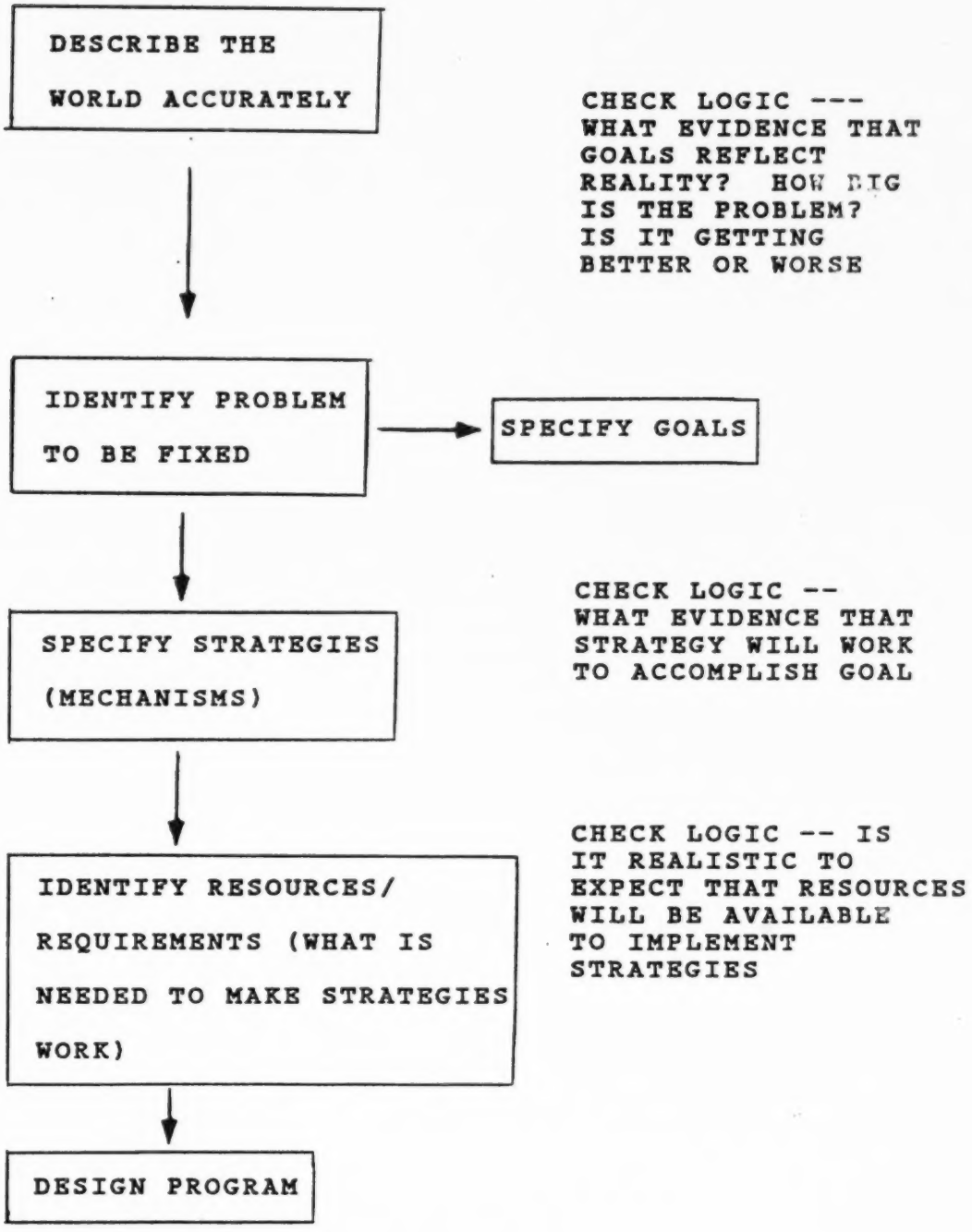
The next step is to isolate any problems or issues, if any, that require attention, or **IDENTIFY PROBLEM TO BE FIXED.** From this assessment, the analyst is now ready to **SPECIFY GOALS.** At this stage, the logic must be tested. Do the goals reflect reality? Is the problem really that big? Is it getting bigger or smaller.

Once these steps are complete, strategies can be developed to address the problems and goals. Unfortunately, **SPECIFY STRATEGIES** is the place where some policy development begins, in isolation from and ignorant of the reality of the policy context. In the flow of a rational analysis, it is at this junture that the strategies should be compared to the goals to determine whether there is evidence to suggest that the strategy will ameliorate the problems identified above.

The next phase is to determine what will be necessary to implement the strategies -- **IDENTIFY RESOURCES AND REQUIREMENTS.** This suggests a canvass of the tangible resources, such as additional funding or manpower, as well as statutory or regulatory changes that are prerequisites to implementation of reforms. This is also a critical point at which to check the logic. At this stage, the analyst asks is it realistic to expect that resources will be available given political and/or fiscal constraints.

Given this comprehensive investigation, the final step is to DESIGN PROGRAMS. Figure 1 displays the policy analysis schema.

FIGURE 1
POLICY-MAKING LOGIC


DESCRIBE THE WORLD ACCURATELY
CHECK LOGIC --- WHAT EVIDENCE THAT GOALS REFLECT REALITY? HOW BIG IS THE PROBLEM? IS IT GETTING BETTER OR WORSE
IDENTIFY PROBLEM TO BE FIXED
SPECIFY GOALS
SPECIFY STRATEGIES (MECHANISMS)
CHECK LOGIC -- WHAT EVIDENCE THAT STRATEGY WILL WORK TO ACCOMPLISH GOAL
IDENTIFY RESOURCES/ REQUIREMENTS (WHAT IS NEEDED TO MAKE STRATEGIES WORK)
CHECK LOGIC -- IS IT REALISTIC TO EXPECT THAT RESOURCES WILL BE AVAILABLE TO IMPLEMENT STRATEGIES
DESIGN PROGRAM

In terms of the analysis described in this project, specific activities related to the policy logic model are as follows:

DESCRIBE THE WORLD -- Interviews were conducted and documents reviewed; draft materials circulated to key informants.

IDENTIFY PROBLEMS -- Results of interviews and document review synthesized to determine consensus; list of problems and issues developed.

SPECIFY GOALS AND CHECK LOGIC -- Problems and goals described in policy paper; paper circulated for review; Sounding Board committee convened.

SPECIFY STRATEGIES AND CHECK LOGIC -- Other states contacted and questions posed regarding impetus and impact of related changes; alternative strategies developed; sounding board committee convened.

IDENTIFY RESOURCES -- Estimates of potential demand and costs developed; sounding board committee convened; implementation of steps defined.

DESIGN PROGRAM -- All project activities and results compiled in final report.

B. Criteria for Assigning Responsibility

In any analysis of a potential reorganization or expansion of state responsibilities, it is necessary to develop criteria for the assignment of new roles or relationships. The following criteria served as background for this analysis:

- History and inclination of the agency
- Nature of the mission and structure of the organization
- Similarity of needs of current and potential clients
- Capacity
- Funding sources
- Client/family interests and preferences
- Legislative mandate

C. Project Parameters

The ensuing analysis is not just limited to services to individuals who meet the federal definition of developmental disabilities since this definition sets limits on age of onset and level of disability. ***Instead, the needs of individuals whose disability occurred at any point in life are included as well as individuals with mild and moderate disabilities.***

Further, the primary focus of the report is on services to adults with disabilities. However, supports to families with children with chronic disabilities and illnesses are included in the discussion. Finally, given the focus on adult services and family supports, special education services are not treated. While we realize that these services are a crucial link in the transition to adult services, resources limited our ability to assess this connection.

III. POLICY CONTEXT

A. Federal Initiatives

Two recent federal initiatives have necessitated attention from state legislatures and have formed the background of policy development for this study. These are the functional definition of developmental disabilities implemented in 1978 and the recently reauthorized Developmental Disabilities Act. These two activities are discussed in this section.

1. Functional Definition of Developmental Disabilities

Issues in the reconfiguration of state developmental disability services and eligibility requirements have been prompted largely by the functional definition of developmental disabilities mandated in Federal Public Law 95-602, the Developmental Disabilities Assistance and Bill of Rights Act (1978). This law does not specifically require that major state agencies change their service eligibility criteria or develop new services. Instead it requires that State Developmental Disability Planning Councils and other bodies supported by federal funds use this definition for planning and research purposes. Some states have adopted the definition in whole or in part and are using it for resource allocation and eligibility determination. The law reads as follows:

> The term 'developmental disability' means a severe, chronic disability of a person which -
>
> a) is attributable to a mental or physical impairment or combination of mental and physical impairments;
> b) is manifested before the person attains age twenty-two;
> c) is likely to continue indefinitely;
> d) results in substantial functional limitations in three or more of the following areas of major life activity:
> 1)self-care, 2)receptive and expressive language, 3) learning, 4) mobility, 5) self-direction, 6) capacity for independent living, 7) economic self-sufficiency; and ,
> e) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

This definition differs substantially from previous definitions of developmental disabilities and also has substantial implications when used for service planning. Some of these differences and implications are outlined below:

- ***Functionally based definition.*** Previous federal and most state definitions were categorical, that is service planning and eligibility were tied to specific diagnostic conditions. Pressure arose from advocacy groups to expand the number of disability categories in order to assure services. However, given the numerous disability groups, a "laundry list" of deserving and eligible groups seemed impractical and undesirable. Advocates recommended instead a definition that "emphasized the complexity, pervasiveness, and substantiality of the disabling conditions" (Hitzing et al. 1985). Further, an emphasis on functional limitations rather than diagnostic conditions fostered an habilitative rather than medical model approach to service delivery. The present federal definition is based on an individual's level of functioning irrespective of the diagnostic condition and no specific diagnostic categories are mentioned.

- ***Focus on persons having substantial limitations.*** One intention of the federal legislation was to focus scarce resources on those persons most in need, and so the legislation specifies that there must be substantial limitation in three of seven major life areas. A functional definition need not imply the exclusion from service of those persons with only mild impairments due to chronic conditions, however a strict interpretation of the federal definition forces that conclusion.

- ***Age of onset criteria.*** The federal definition specifies that the disabling condition must have manifested itself before age 22. This criteria is intended to focus services on a cohort of persons who have experienced disabilities during childhood, where such disabilities may have interfered with normal developmental processes and who therefore have similar habilitative service needs. Expanding the age of onset criteria into adulthood could result in including substantial numbers of persons who may be outside the intent and usual service provision of a developmental disability agency (e.g. adults with AIDS, diabetes, severe heart conditions, stroke) and without an upper limit of age on onset (e.g. age 55) numerous elderly persons with severe functional impairments could be deemed eligible. However, limiting service to persons with a manifestation under age 22 may very arbitrarily exclude persons in substantial need of services consonant with a the mandate of a developmental disabilities agency. For example, there is no difference in the needs of persons with spinal cord or head injury or with multiple sclerosis if their disability manifested itself at 20 or at 22 years of age.

- ***Change in numbers of persons eligible for services.*** Of main concern to state agencies is whether adoption of a functional definition will substantially change the numbers of persons eligible for services. Research indicates that a focus on substantial limitations will reduce the numbers of persons eligible who have mild impairments who had otherwise been

eligible, for example persons with epilepsy or mental retardation, (Lubin, Jacobson & Kiely 1982; Morrison, Smull & Sachs 1984; HSRI 1988). However, the definition also opens services to a number of low incidence disability groups that had been previously ineligible (e.g. spina bifida, cystic fibrosis). There are disparate findings with respect to potential changes in the numbers of persons eligible. These are outlined in more detail in Section V of this report.

- ***Change in range of services offered.*** Given the potential inclusion of many new disability groups, some change in the character of services offered by a developmental disability agency is likely. "New services will have to be developed, some old patterns abandoned, and agencies will of necessity learn to become more flexible in their dealings with service recipients" (Hitzing, Pealer, & Reardon 1985). Although there is clearly no single solution to address all of the diverse needs of persons meeting the functional criteria, there is a commonality of general service needs across all groups. These service needs can be grouped into four categories: 1) generic services (e.g., transportation, housing); 2) case management services (e.g.,. service brokering, information and referral, follow along); 3) specialized support services (e.g. physical therapy, behavioral consultation); and 4) advocacy and protective services.

In light of the considerable implications of adopting a functional definition, it is useful to know how many states have done so. Hitzing, Pealer, & Reardon (1985) conducted a survey of how individual state service agency's are defining and determining eligibility for developmental disability services. "The majority of states responding reported that they use a categorical or mixed functional/categorical definition similar to the 'old' federal definition (P.L. 94-103)" (Hitzing, Pealer, & Reardon 1985). However, as the authors point out, although many states have changed the name of the state agency for mental retardation to developmental disabilities, this does not necessarily indicate a change in focus to all persons with developmental disabilities. Fifty-two percent of the respondents in the above study reported that in terms of actual service delivery their state agency focuses on persons with mental retardation and 16% reported that their agency focuses on persons having mental retardation and other specified disabilities, whereas only 13% reported that they focus on ***all*** developmental disabilities. Twenty-one percent of the respondents reported adoption of the federal definition of developmental disabilities, and 6% reported adoption of a modified version of the federal definition. The remaining respondents (57%) reported use of a categorical definition whereas 15% reported use of a mixed functional/categorical definition (Hitzing, Pealer, & Reardon 1985). A description of different state experiences in adopting a functional definition is presented in Section IV.

2. Reauthorization of the Developmental Disabilities Act.

Another major impetus to a reexamination of the organization of services to persons with disabilities is the new language in the reauthorization of the federal Developmental Disabilities Act. According to Senator Lowell Weicker (Connecticut) in his remarks on the bill on the Senate floor:

> Specifically, the bill requires State Planning Councils to do a policy analysis to determine the extent and scope of services available to *all* people who are developmentally disabled within the state. This provision was added based on testimony indicating that many people, particularly individuals with a severe physical disability but no mental disability, are not able to access services, either through state agencies or in some cases, through programs and services generated through the Developmental Disabilities Act. The current definition of developmental disability is a functional definition which eliminates categories and is intended to make eligibility for services based on the interaction between a person and his/her environment rather than on a specific diagnostic label.

The new law requires that by April 1, 1990, the State Planning Council must transmit a final report to the Governor and the legislature of the state including: a) recommendations on the most appropriate agency or agencies of the state to be designated as responsible for the provision and coordination of services for persons with developmental disabilities who are traditionally underserved, such as persons with developmental disabilities attributable to physical impairment, dual mental impairments, a combination of physical and mental impairments, and such other subpopulations of persons with developmental disabilities (including minorities) as the State Council may identify; and b) the steps taken to include the data and recommendations in the State Council's ongoing advocacy, public policy, and model service demonstration activities.

The Connecticut Council's support for the policy analysis included in this report in large measure anticipated the requirements of the new Act.

B. State System

1. Previous System Analyses

Concern with organizational issues in Connecticut's service delivery system did not begin with this project. In fact, in the 1985-1986

budget, Governor William A. O'Neill recommended an appropriation of $150,000 for a Secretary of Human Services (p. 62). The General Assembly did not accept this recommendation and instead chose to address issues related to service integration and coordination through further study.

Two major studies have preceded our efforts. The first was conducted by Research Triangle in 1986 and was titled *The Coordination and Delivery of Human Services in Connecticut: A Report with Recommendations to the Commission to Study Human Services.* This study was authorized by the Connecticut General Assembly's Public Act No. 85-546 enacted in July, 1985. This act established a ten member bipartisan commission to study coordination and service integration issues in Connecticut's human services delivery system. The Act also specified that an independent contractor should be hired to assist the commission members in their investigations. Research Triangle Institute (RTI) was selected to fulfill this role.

The RTI approach included both key informant interviews and document review. Issues addressed in this report included: organization of human services, the role of the Office of Policy and Management and the Office of Fiscal Analysis, the role of the Governor, the use of task forces to deal with critical issues, district-based delivery of services, and the effects of economic prosperity. The report concluded with a recommendation for a "Super Commissioner" of Human Services to coordinate the delivery of services.

The second study was commissioned by the Connecticut Department of Human Resources in 1986/87 and was conducted by Connecticut Research Associates (1987). This study was similar to the RTI study described above in that it explored issues of service coverage, coordination and integration through a combination of document reviews and key informant interviews. However, its focus was narrower than the RTI study. Whereas the RTI study focused on all human services in the state, the Connecticut Research Associates study examined only those services provided for persons with disabilities. Limiting its focus further, the study excluded the Department of Mental Retardation and the Department of Mental Health services. Issues addressed included: the current state policy regarding people with disabilities, state services for persons with disabilities, and problems with the current system. The report concluded with a recommendation that the Department of Human Resources assume the position of "lead agency" for disability issues.

The two central policy options that grow out of these studies are: the creation of the position of Secretary of Human Services recommended by Research Triangle Institute and the "lead agency" concept recommended by Connecticut Research Associates. The authors of the RTI study, after conducting key informant interviews and reviewing relevant documents, evaluated the human services delivery system in Connecticut and concluded:

> ...first,...the system is responsive to the needs of persons it currently serves, but is less responsive to persons who do not fit established categories, or whose needs are broader than one agency can serve effectively. Second, the cost of maintaining the system is inherently high because each agency requires its own administrative staff and other resources required to operate independently. Third, as the nature of human service delivery undergoes changes in the next few years, the specialization of agencies in Connecticut will make it difficult to take advantage of opportunities to improve service and reduce costs. (RTI, 1986 p. 60)

In response to these system characteristics, RTI recommended the eventual establishment of a Department of Human Services. The first step recommended in this process was the creation of the position of Secretary of Human Services. This person would be appointed by the Governor, with the approval of the General Assembly. The Secretary's responsibilities would include system planning, development of an overall human services budget, monitoring service effectiveness and efficiency, and directing the efforts of a new human services cabinet whose membership would include the commissioners and executive directors of the state's human service departments and agencies. In addition, RTI recommended that the state be divided into six human service regions so that regional boundaries would coincide for all human service agencies. The new Secretary of Human Services would coordinate the activities of and supervise regional administrators from each of these six areas.

The second major policy initiative that has been recommended is the "lead agency" concept suggested by Connecticut Research Associates. Having followed procedures similar to those used by RTI, the authors evaluated the system of services for persons with disabilities. This analysis excluded the Departments of Mental Retardation and Mental Health. The conclusions of this study are very similar to those articulated by RTI:

> The report shows that services for people with disabilities are provided by thirteen different state agencies, and that none of those agencies has the responsibility to evaluate and plan for the global needs of people with disabilities. This results in an uncoordinated system of providing services, and gaps in services that preclude individuals from reaching their full potential. (Connecticut Research Associates, 1986, iii)

Unlike the "super agency" concept recommended by RTI, the author of this study recommended that the departmental structure remain essentially intact and that the Department of Human Resources (DHR) should be designated as "lead agency" for disability services. Rather than establishing a segregated system of services for persons with disabilities, it was recommended that DHR as lead agency should:

> ...assume the responsibility for identifying barriers to community participation by people with disabilities and for seeking solutions to those problems that utilize generic systems to the greatest degree possible. The lead agency should be a catalyst for system-wide change, not the provider of services for a defined population. (p. iv)

Consistent with this general principle, the responsibilities of the lead agency included: coordinating state policy; collecting, organizing, and disseminating relevant information; coordinating training of state employees; planning statewide services; and facilitating interagency collaboration.

In conclusion, the above review of the policy recommendations advanced to solve system discontinuities suggest two somewhat polar approaches to system reorganization. The first, put forth by RTI, would significantly alter the current organization of services in the state and would reconfigure much of the current human services apparatus. This approach is more in line with policy initiatives taken in the 1970s under the rubric of "services integration." This approach, while maximizing the potential for service coordination and uniformity, also tends to mask the very real and unique differences among human services constituencies and blunts accountability and advocacy on behalf of particular groups of individuals.

The second approach, advanced by Connecticut Research Associates, would result in only minor dislocation to the existing system and would establish a "lightning rod" agency to coordinate services for persons with physical disabilities. This latter approach, however, also has some drawbacks. First, it assumes that services can be made more rational and coordinated through the energies and activities of a small organization lodged within a much larger generic agency. Second, it does not address systemic problems that may face persons with mental disabilities. Given these drawbacks, the proposal from the Connecticut Research Associates should be seen as one potential change within a cluster of changes needed to make the service system for persons with disabilities in the state more rational and responsive.

2. Overview of the Current System

Three very detailed overviews or inventories of the state's services for persons with disabilities have been completed recently. The first of these is contained in the Research Triangle report and was compiled by the Connecticut Office of Legislative Research. This inventory lists all state departments providing human services along with their total budgets broken out according to state and federal share. In addition, the inventory lists all major human service programs within each agency and notes the budget and purpose of each program. Data were derived from the Governor's budget for FY 1985/86 (RTI, 1986, Appendix B).

A second inventory was compiled by Connecticut Research Associates in their study for the Department of Human Resources. This inventory lists "...state supported programs that provide services for disabled, non-elderly individuals who are not eligible to be served by the Department of Mental Retardation or the Department of Mental Health." Information available in this report includes program descriptions, eligibility criteria, and budget figures. Data were derived from the 1986-1987 budget (Connecticut Research Associates, 1987 Exhibit 1 and Appendix 4).

The third inventory was developed by the State of Connecticut Planning Council on Developmental Disabilities (1985). This document contains program descriptions and budget figures for programs serving all persons with disabilities, including those eligible for services through the Department of Mental Retardation and the Department of Mental Health.

Summary of Inventory Data. These service inventories contain a wealth of information. It makes little sense to expend further resources compiling yet another compendium of services for persons with disabilities. Instead, we refer the reader to these three excellent resources and have focused our own efforts on constructing a brief summary of existing documents and compiling an inventory of major program changes that have been recommended in the Governor's budget for 1987/88.

The delivery of human services is a billion dollar industry in Connecticut. In 1985/86 (the last year for which actual as opposed to estimated figures are available), expenditures for human services reached $2,039,017,229. State dollars accounted for $1.318,967,810; the federal share was $720,049,419. Services for persons with mental retardation cost $212,522,331 ($207,002,069 in state funds and $5,520,262 in federal funds). Services for persons with other handicapping conditions cost $32,504,520 ($10,393,474 in state funds and $22,111,046 in federal funds) (RTI, 1986 pp. 34-37).

In Connecticut, services for persons with disabilities are delivered through fourteen separate agencies. Collectively, these agencies sponsor 96 major programs serving persons with physical and mental disabilities (Planning Council on Developmental Disabilities, 1985). The departments are:

- Department of Housing
- Department of Administrative Services

- Department of Motor Vehicles
- Department of Labor
- Department of Environmental Protection
- Department of Health Services
- Department of Mental Retardation
- Department of Mental Health
- Department of Transportation
- Department of Human Resources
- Department of Income Maintenance
- Department of Education
- Department of Children and Youth Services
- Judicial Department

In terms of the amount of money devoted to services for persons with disabilities, two agencies play a predominant role: the Department of Mental Retardation (DMR) and the Department of Education (DOE).

The Department of Mental Retardation had total 1985/86 expenditures of $190,968,311; estimated 1986/87 expenditures are $249,781,096 (Governor's Budget, 1987/88, p. 403). In 1985, DMR served 8,743 persons (p. 401). The services provided to (or on behalf of) these individuals included:

- Resource Services
  - * case management

  - * family support services
  - * specialized support and health services
  - * staff development and training
- Day Services
  - * early intervention
  - * Unified School District #3
  - * sheltered workshop programs
  - * supported employment program
  - * adult day treatment services
  - * elderly enrichment
  - * recreation/social development
- Residential Services
  - * community training homes
  - * community living alternatives
  - * campus units
  - * other private residential facilities

The Department of Education had a total 1985/86 budget of $$867,448,795; estimated 1986/87 expenditures are $964,788,467 (p. 549). Two very large DOE programs focus on persons with disabilities: special education and rehabilitative services. The department's special education program had actual expenditures of $143,223,268 in 1985/86 and estimated 1986/87 expenditures of $159,448,764 (p. 548). In 1985/86,

77,825 children were served in this program (p. 559). Rehabilitative services had 1985/86 expenditures of $22,300,175 and estimated 1986/87 expenditures of $24,399,551 (p. 548). Rehabilitation Services served, 14,349 disabled clients in 1985/86.

Recommended Changes in the 1987/88 Budget. Major program changes have been noted in the Governor's Budget for 1987/88. Those changes that relate to services for persons with disabilities are listed in Exhibit 1.

EXHIBIT 1

PROGRAM CHANGES RECOMMENDED IN THE GOVERNOR'S 1987/88 BUDGET

OFFICE OF POLICY AND MANAGEMENT

- Human Services Coordination A unit to coordinate interagency purchase of service procedures and policies of state human service agencies ($150,000).

- Tax Relief for Elderly and Disabled Homeowners and Renters P.A. 86-409 included totally disabled persons who qualify under the income criteria ($150,000).

DEPARTMENT OF LABOR

- Employment of Handicapped/Interagency Job Bank for Workers with Disabilities Funds are recommended to better promote employment of the handicapped and to develop a job bank designed to better assist the disabled to obtain employment ($75,000).

PROTECTION AND ADVOCACY FOR HANDICAPPED

- Reducing Response Time and Improving Quality of Service Funding for additional advocacy staff is recommended due to increased

advocacy workloads and longer response times ($74,000).

- Expanding Outreach to Minority Persons with Disabilities To expand the minority outreach program (currently only in Hartford) to other major urban areas in the state ($47,000).

- Abuse of Persons with Mental Retardation Funds recommended for additional investigatory staff due to backlogs causing lengthy delays ($50,00).

- Community Transition Project Additional advocate positions for Mansfield Training School to implement CARC vs Thorne court decree (199,000).

- Ensuring Legal Rights for Persons with Disabilities Funding for contractual services to provide legal services to disabled persons ($80,000).

- Advocacy and Abuse at Southbury Additional funding to contract for advocacy services to mentally retarded adults at Southbury ($50,000).

DEPARTMENT OF HEALTH SERVICES

- Respite Care Traumatic Brain Injury (TBI) The Respite Care Grant is increased to serve traumatic brain injury clients ($50,000).

DEPARTMENT OF MENTAL RETARDATION

- Expand Case Management Services Establish 52.5 new positions to lower staff to client ratios to 1:40 ($1,047,817).

- Expand Support Services to Families of Clients Living at Home Provide respite care for 1060 families. Establish 6 respite coordinators and 6 family support coordinators. Provide funds for educational lending centers and home modifications ($554,340).

- Administration of Medication Establish 6 nursing positions to

train clients and staff to administer medications ($139,600).

- Expand Access to Community-Based Health Services Additional funds are provided to supplement medical services provided under the State Medicaid program ($200,000).

- Expand Training Capabilities Expand training staff by 9 positions. Provide funds for release time for Adult Day Program staff for consultant contracts ($448,710).

- Expand Placements to Integrated Settings Funding to place 160 clients in integrated nurseries and day care centers ($150,000).

- Expand Supported Employment Program Funding to place 483 additional clients in Supported Employment Programs ($3,189,485).

- Expand Adult Day Treatment Services Funding to place 207 additional clients in Adult Day Treatment Programs ($2,558,720).

- Expand Community Training Home Program Funds for 60 new community training home placements, respite care for all CTH placements and a $25 increase in the monthly children's clothing allowance ($471,900).

- Salary Adjustments for Private Residential Workers Funds to increase salaries and reduce turnover in private group homes ($8,720,110).

- Expand Community Placements Provide placements in community residences for 325 additional persons ($11,125,800).

- Implementation of New Rate-Setting System Funds for one-time certified audits of 44 provider organizations to obtain baseline data for new rate setting system ($770,000).

- Develop Special Programs for Assaultive Clients and Dually-Diagnosed Funds to develop new programs to treat dually-diagnosed and aggressive/assaultive clients including psychiatric and medical diagnostic teams, and inpatient psychiatric/ behavioral diagnostic, stabilization and follow-up support programs ($2,000,000).

- Expand Service at Southbury Training School Establish 40

permanent and 104 temporary positions to enhance services at Southbury ($1,597,134).

- Continue Phase-Down at Mansfield Training School Partial year costs of 88 positions are reduced at Mansfield in anticipation of clients moving to the community (-$507,790).

DEPARTMENT OF TRANSPORTATION

- Handicapped Access to Public Transportation Ensures the availability of adequate public transportation services for the handicapped ($350,000).

DEPARTMENT ON AGING

- Expanded ConnPACE Program Increase income eligibility levels for the elderly and add permanently and totally disabled persons, between ages 18 and 65 to expand coverage of pharmaceutical assistance program ($3,317,000).

DEPARTMENT OF HUMAN RESOURCES

- Administration of Program for Persons with Disabilities New 3 staff unit to serve persons with disabilities ($97,000).

DEPARTMENT OF INCOME MAINTENANCE

- Community Services Annualized cost due to expanded services for Departments of Mental Retardation and Mental Health clients by continuing to strengthen community support for deinstitutionalized persons ($338,000).

- Work Disregard Increase work disregard for eligibility determination for disabled clients from $50 to one-half of earnings ($240,000).

- Caseload and Usage Increases Includes $3,659,423 for long term care and group homes for the mentally retarded, and $2,487,388 for hospital services ($8,316,835).

DEPARTMENT OF EDUCATION

- Increased Costs for Special Education Increased reimbursable costs of special education to towns ($19,520,000).

- Establish Funding for Extended-Day Kindergarten Funds to maintain, expand, or establish extended day kindergarten in local districts ($2,000,000).

- Planning and Piloting a Birth to Three Program Plan and pilot a program of comprehensive health and educational care for handicapped children from birth to three ($350,000).

DEPARTMENT OF EDUCATION (REHABILITATION SERVICES)

- Independent living, Part A Program Add 5 positions to expand rehabilitation services for individuals who are severely disabled with no potential for employment ($80,000).

- Driver Assessment for Disabled Individuals Purchase equipment necessary to improve driver assessments. An assessment is made of the specialized automobile equipment needs of the disabled ($50,000).

- American School for the Deaf, Increased Costs Increase support within inflationary guidelines ($151,849).

- American School for the Deaf-- Maintain Quality Teaching Staff Improve teacher salaries ($200,000).

COMMISSION ON DEAF AND HEARING IMPAIRED

- Additional Part-Time Interpreters Increase of five part-time

interpreters ($15,000).

- Inflationary Adjustment on Federally Funded Positions Fund salary adjustment increases on federally funded positions ($13,600).

- Continue Telecommunication Devices for the Deaf (TTY) Partial replacement of special funding to offset reduced contribution by SNETCO ($25,000).

DEPARTMENT OF CHILDREN AND YOUTH SERVICES

- Subsidized Adoption Rate Increase rate paid to assist families in adopting hard-to-place children ($81,000).

In conclusion, the above review of the current system of services for persons with disabilities in Connecticut reinforces the almost universal view of those connected with the delivery and receipt of services in the state -- the present organization of services perpetuates a fragmentation of services for many persons with disabilities and places the onus for integrating a service plan on the individual and his or her advocate. While initiatives have been proposed and implemented over the past few years to rectify both discontinuities in services and disparities among groups of disabled individuals, those steps have been incremental and to date have not affected how the overall system is organized and how priorities are set.

3. Clients Served

Adults with disabilities receive services through at least 14 state agencies. However, the three largest are the Department of Mental Retardation, the Department of Human Resources and the Division of Rehabilitation Services. Figures on the populations served by each of these agencies follow in Tables one through five.

The Department of Mental Retardation

In 1986, the Department of Mental Retardation was serving 8,864 clients (Tables 1 & 2). This was up from 7,912 clients in 1980. The majority of these clients were adults, aged 21 to 64. A slight change in the age distribution occurred during the interval between 1980 and 1986. The youngest age group (0 to 4) increased from 5% to 9% of the total clientele. Table 3 distributes clients across levels of

DEPARTMENT OF MENTAL RETARDATION

CHARACTERISTICS OF CLIENTS

Table 1
Clientele by Age Level

Age	5/80 No.	5/80 % Tot.	10/86 No.	10/86 %Tot.
0-4	428	5.4	800	9.0
5-17	1484	18.8	971	11.0
18-20	584	7.4	421	4.7
21-64	5068	64.0	6192	69.9
65+	348	4.4	480	5.4
Total	7912	100.0	8864	100.0

Table 2
Clientele by Retardation Level

	5/80 No.	5/80 %Tot.	10/86 No.	10/86 % Tot.
Mild	1,424	18.0	1,768	19.9
Moderate	1,877	23.7	2,032	22.9
Severe	1,506	19.0	1,529	17.3
Profound	1,880	23.7	1,904	21.5
Other	1,240	15.6	1,631	18.4
Total	7,927	100.0	8,864	100.0

Table 3
DEPARTMENT OF MENTAL RETARDATION

FIVE YEAR SERVICE PROJECTIONS

Estimated Number of Individuals

	1987	1992
RESIDENTIAL SERVICES		
• Comm. Train. Homes	500 (9%)	852 (12%)
• Comm. Living Arrgmnts.	1885 (32%)	4253 (60%)
• Campus Res. Units	2270 (39%)	1385 (20%)
• Priv. Cong. Res. Fac.	1211 (21%)	550 (8%)
DAY SERVICES		
Privately Operated		
• Sheltered Employment	3095 (64%)	2295 (29%)
• Opportunities for Older Adults	287 (6%)	1560 (20%)
• Community Experience	455 (9%)	697 (9%)
• Supported Employment	959 (20%)	3434 (43%)
DMR Operated		
• Adult Day Programs	2480	1399
• Unified School District	889	1079
CASE MANAGEMENT		
• Service Recipients	9270	11,800
FAMILY SUPPORT		
• Families Receiving Respite Services	635	2150

retardation remained fairly constant during this period. Table 3 identifies some major elements of the Department's five year plan. In residential services, the plan calls for a major change in the relative importance of community living arrangements. The plan proposes that 60% of persons receiving residential services will be living in community living arrangements in 1992 as opposed to the current 32%. Corresponding decreases in the use of campus residential units (from 39% in 1987 to 20% in 1992) and private congregate residential facilities (from 21% in 1987 to 8% by 1992) are also proposed.

With respect to day services, a major shift from sheltered employment to supported employment is anticipated. Currently, 64% of clients receiving day services are in sheltered employment settings. The plan expects this figure to fall to 29% by 1992. Similarly, the figures for supported work are expected to increase from 20% to 43% during the interval.

Department of Human Resources

The Department of Human Resources provided services to 1745 clients aged 65 or older and 1090 non-elderly persons with disabilities in 1987 through its Adult Services programs (see Table 4). Services provided included adult companion, adult day care, choreperson, housekeeper, homemaker, and home delivered meals. In its Personal Care Assistance program, the department provided grants to 47 persons with severe disabilities in fiscal year 1987. The Parent Subsidy Aid program provided grants and/or social work services to 36 families with physically or developmentally disabled children. Finally, DHR administers a grant program to support residential services (two group homes) for persons with traumatic brain injury and supplies counseling to approximately 400 individuals with brain injury and their families.

Division of Rehabilitation Services

As Table 5 indicates, DRS provided services to 15,400 clients in fiscal year 1985-1986. 2,184 clients were rehabilitated. Forty-eight percent of these clients were severely disabled according to the U.S. Department of Education criteria. Thirty-two percent of these clients had psychiatric disorders (including drug and alcohol), 18% had mental retardation, 18% had an orthopedic impairment, and 16% had a hearing impairment. The distribution of clients in other categories is contained in Table 5. More current information is anticipated from the Division when its annual report becomes available.

Table 4

DEPARTMENT OF HUMAN RESOURCES

ADULT SERVICES

Eligible Population
Elderly Persons and persons with physical or mental disabilities who meet the Department's income and asset criteria.

Services Provided
- Adult Companion
- Adult Day Care
- Choreperson
- Housekeeper
- Homemaker
- Home Delivered Meals

Monthly Caseload (SFY 1987)

• Clients 65 Years of Age or Older	1745
• Clients 18-64 (people with disabilities)	1090

PERSONAL CARE ASSISTANCE

Eligible Population
Persons with severe disabilities who are either employed or employable within six months and meet the Department's income guidelines.

Services Provided
Grants of up to $7,3000 for a personal care attendant.

Clients Participating (SFY 1987)
- 47 clients
  - 21 full grants
  - 26 partial grants

PARENT SUBSIDY AID

Eligible Population
Natural parents of physically or developmentally disabled children.

Services Provided
- Grants of up to $2,000
- Comprehensive social work services

Families Participating (SFY 1978)
- 36 families

TRAUMATIC BRAIN INJURY PROGRAM

Eligible Population

Persons with traumatic brain injury and their families.

Services Provided

- Counselling provided to 400 persons with traumatic brain injury and their families.
- Group homes -- two homes proposed in the 1987/1988 budget.

Table 5

DIVISION OF REHABILITATION SERVICES

SERVICE PROFILE (1985-1986)

- Clients Served 15,400

- Services Provided
  - * Medical and Vocational Evaluation
  - * Physical and/or Mental Restoration
  - * Guidance and Counselling
  - * Training
  - * Job Placement
  - * Postemployment Services

TYPES OF DISABILITIES OF REHABILITATED CLIENTS 1985-1986

• Psychiatric Disorder (includes alcohol and drug abuse)	32%
• Mental Retardation	18%
• Orthopedic Impairment	18%
• Hearing Impairment	16%
• Learning Disability	6%
• Visual Impairment	2%
• Absence/Amputation of Limb(s)	1%
• Miscellaneous	7%
Total Clients Rehabilitated	2,184
Percent Severely Disabled (According to U.S. Dept. Of Education Criteria)	48%

C. Strengths and Limitations

In order to make recommendations regarding the future direction of services for persons with disabilities in Connecticut, it is important to first canvass the perceptions of persons in the system regarding the ways in which the system is functioning and the feasibility and attractiveness of particular policy options. In order to conduct this assessment, project staff made numerous site visits in the state both to observe programs and to solicit the views and opinions of a representative range of individuals. As noted earlier, provider and consumer forums were also held to gain input. The following discussion outlines the strengths that were noted, the problems sited, and the potential solutions advanced.

1. Strengths of the Current System

Most of the people interviewed felt that Connecticut was entering into a new era with respect to services for people with disabilities. With respect to mental retardation, they pointed to the court order that currently influences the direction of mental retardation services and requires the Department of Mental Retardation to move aggressively to create and expand community based services. A large number of those interviewed also noted the salutory influence of new leadership at DMR and the positive, value oriented policies -- such as community integration -- that were beginning to emerge. Providers and consumers alike noted that the decree and the new leadership together had created real strides in the mental retardation system in the last two years including the preparation of a mission statement, the design of an improved case management system, the beginnings of a comprehensive quality assurance system, the development of an individualized client planning process, and the recruitment of staff with commitment and program expertise.

Also, with respect to leadership, a number of system observers were expectant that the new administrator at the Department of Human Resources would stimulate that agency to more progressive and client-centered directions. The commitment evinced by this leadership to represent and advocate for the interests of persons with disabilities was also cited as a positive change in the policy environment.

A number of persons noted that leadership in the state legislature was increasingly supportive of new directions in the provision of services to persons with disabilities including the development of an expanded independent living network as well as the expansion of community based services.

The presence of the Connecticut Coalition of Citizens with Disabilities was further noted as a strength in the state. The

Coalition has served as a forum for the discussion of problems affecting persons with a range of disabilities and the leadership of the Coalition has actively attempted to reach out to persons with mental as well as physical disabilities.

The Connecticut Developmental Disabilities Council was also mentioned as one of the strengths among persons in the disability community. According to many of those contacted, the Council has been a leader in introducing key actors in the state to important advances in the state-of-the-art both with respect to program as well as philosophical approaches to the delivery of services. The Council, unlike councils in some other states, has reached out to a range of disability groups and has not been content to limit its activities to the conventional groups encompassed within the term developmental disabilities.

Finally, a number of individuals mentioned the size of the state as an important facilitating factor. Its smallness enhances communication and makes the dissemination of information and training of key personnel more expeditious.

2. Weaknesses in the Current System

The major weakness addressed by many of those interviewed was the absence of a single entry point into the system that opened the door to the range of services required by persons with disabilities including housing, income support, training and employment, transportation, and recreation. With the exception of persons with mental retardation, no other group of individuals with disabilities could identify the one agency that they could go to that could assist them in brokering needed services. In addition, among those agencies that do serve persons with disabilities, interviewees mentioned the lack of consistent eligibility criteria, differences in geographical locations, and wide-ranging differences in philosophy regarding service provision.

The fragmented nature of the service system is to some extent compounded by the way in which state government had conventionally been managed in the state. Unlike other states, Connecticut has not created any mediating structures between the heads of discrete departments and the Governor's Office such as a "secretariat" that would combine a range of human services and/or health concerns. Additionally, the heads of state departments are rarely if ever convened by the Governor to grapple with cross-agency problems or to coordinate like program activities. As a result, the various state departments in Connecticut, perhaps even more so than in many other states, tend to function as autonomous authorities. [During the course of this project a human services cabinet was created].

Persons interviewed who were familiar with the mental retardation system were concerned that while the philosophy of DMR had certainly changed, the reality of the service did fully reflect the new vision. One interviewee pointed to the fact that several class members had been returned to the state's institutions following community placement and indicated that community capacity to serve individuals with severe disabilities was still lacking in many areas of the state. Others noted that any change of the magnitude facing DMR takes a long time and that the system was going through a "shake-down" period that made it somewhat vulnerable.

Attitudes in the state about the potential of individuals with disabilities was mentioned prominently by many consumers of services as a weakness in the system. They felt that many service providers and some family members still adhere to antiquated notions about what persons with disabilities are able to achieve and are supporting more restrictive and paternalistic programs as a result. Many expressed further concern that these attitudes were likely to shape solutions for persons with disabilities who have previously been excluded from the system such as persons with traumatic brain injury. As one consumer noted, "I just hope they don't make the same mistakes we did." (e.g., support for more restrictive group home settings).

There seemed to unanimous agreement among those contacted that reforms are necessary to make the Division of Rehabilitation Services a more responsive and accountable agency. Its current position within the Department of Education appears to have diminished its visibility as well as reduced its status vis-a-vis other Department of Education programs. Given the significance of the programs under its jurisdiction and the increasing importance of alternative approaches to work and community living, almost all agreed that an organizational change was necessary to bring about reform in the administration of vocational rehabilitation in the state.

Turnover among the personnel serving as case managers and direct care staff was noted as a growing problem. While Connecticut is not alone in confronting this problem, it is important to keep such personnel constraints in mind as recommendations for expansion and changes in agency mandates are proposed.

3. Gaps in Service Delivery

The following list provides a summary of the service system gaps noted by those interviewed and those attending the public forums:

1. A lack of services for particular target groups of individuals with disabilities including individuals with traumatic brain injury, severe learning disabilities and dual

problems of mental illness and mental retardation.

2. Absence of a cross-agency case management structure.

3. Inadequate grass roots advocacy for individual clients.

4. Inadequate resources for the provision of services to persons with challenging behaviors and complex medical needs.

5. Insufficient supply of housing for persons with all forms of disability.

6. Inadequate transportation mechanisms tailored to individual needs and schedules.

7. Lack of a systematic and organized system of support for families with members with disabilities including those with chronic illnesses.

8. Presence of antiquated program models that reinforce dependency and community isolation.

9. Lack of information regarding the efficacy of services provided to persons with disabilities and the outcomes of such services.

10. Lack of ongoing training among professionals providing services to persons with disabilities regarding the values of normalization and individualization.

11. Insufficiently funded personal care attendant program.

12. Lack of consumer involvement in system planning and priority setting.

13. No systematic coordination for planning services following graduation from special education.

14. Lack of any centralized or regionalized entity that provides information regarding service availability and location.

15. Little or no priority placed on those interventions likely to stimulate natural community supports and non-facility based living arrangements.

4. Potential Solutions

During the course of the interviews, respondents were asked to comment on a range of potential solutions to the system discontinuities and gaps noted above. The themes that emerged from these discussions follow:

- Almost all of those interviewed resisted the idea of creating a new agency that would bring together multiple services to persons with disabilities (e.g., transportation, housing, employment, etc.) because they saw this as another "layer of bureaucracy" that would not necessarily result in improved service delivery.

- Those advocating for the needs of persons with physical disabilities were concerned that a designation of the Department of Mental Retardation as the lead agency to coordinate services would result have two negative effects. First, the orientation of DMR, because of the nature of the clientele, is seen as more paternalistic and therefore inconsistent with independent living objectives. Second, persons with physical disabilities would be reluctant to become associated with an agency that has previously served persons with mental retardation given their battles to overcome the stigma already associated with their disability.

- Most of those interviewed seemed to agree that what was required was a new coordinating function both at the local as well as the state level -- not necessarily a "super agency" that would merely move the pieces of the system around.

- While many disability advocates are in agreement that a functional definition of eligibility would eliminate the discrimination that they currently experience with categorical eligibility criteria, there is also concern about the loss of identity that would result if a Department of Developmental Disabilities is formed. Given the power of mental retardation advocates and the level of funding for mental retardation, some advocates were concerned that their constituents and their concerns would not receive priority attention.

- Advocates for persons with physical disabilities were by and large supportive of the recommendation by the Connecticut Research Associates to create an Office of Disabilities in the Department of Human Resources.

- There was general agreement that the Division of Rehabilitation Services should be moved out of the Department of Education. There was disagreement, however, regarding where its new home should be. The options are that it remain independent, be added to the Department of Human Resources or moved to the Department of Mental Retardation.

- Some of the advocates interviewed registered pessimism regarding the ability of the Division of Rehabilitation Services to alter its orientation and recommended that the responsibility for any future independent living centers be given to the Department of Human Resources.

- Representatives of single disability state agencies were opposed to any movement into an integrated disability agency. They also expressed concern that such a move would be detrimental to the special concerns and needs of their constituencies.

- Many of those contacted noted that while the creation of a Department of Developmental Disabilities had distinct merits, the addition of such responsibilities to the current Department of Mental Retardation would place a burden on an already overloaded agency in the midst of substantial change and disruption.

These comments suggest that most of those who are participants or recipients in the current system see the need for change and improved service coordination. Virtually everyone stipulated that there was a need to develop services to those who currently have no "home" in state government including persons with traumatic brain injury, serious learning disabilities, and dual mental disabilities. However, there is not a strong consensus regarding the way in which services should be reorganized to resolve commonly agreed-upon problems.

The strongest implication that emerges from this initial review is that no one solution will solve the complexity of issues identified. The creation of a Department of Developmental Disabilities will not necessarily improve the performance of the Division of Rehabilitation Services. The designation of an Office of Disabilities within the Department of Human Resources will not necessarily guarantee improved interagency cooperation. The organization of a "super agency" for disability will not ensure that the needs of a particular disability group will be met.

IV. OTHER STATE EXPERIENCES IN USING A FUNCTIONAL DEFINITION OF DEVELOPMENTAL DISABILITIES

This section reviews how other states have grappled with creation of a department or agency of developmental disabilities and the adoption of a functional definition for eligibility determination. During the course of this project, key staff were interviewed and documents were reviewed in a number of states. Four states were selected that had had the most experience in this endeavor and that also represented the range of policy options and outcomes. Efforts in New Jersey, Maryland, Ohio, and Connecticut are reviewed below. This is followed by a brief outline of lessons that can be learned from other states.

A. New Jersey

In April, 1985, New Jersey changed its Division of Mental Retardation to the Division of Developmental Disabilities and expanded the Division's mandate to include persons with a wide range of developmental disabilities. Underlying this organizational change was a change from a categorical to a functional definition for service eligibility. For New Jersey, this was a particularly profound change since the Division of Mental Retardation had not, at that point, even expanded its service mandate to include cerebral palsy, epilepsy, and autism -- a change that has occurred in many other states. The transition to a Division of Developmental Disabilities is part of a three year planning project.

The definition that has been adopted by New Jersey is similar to the federal definition and reads as follows:

> "Developmental disability" means a severe, chronic disability of a person which: (1) is attributable to a mental or physical impairment or a combination of mental or physical impairments; (2) is manifest before age 22; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of major life activity, that is, self-care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living or economic self-sufficiency; and (5) reflects the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of life-long or extended duration and are individually planned and coordinated. Developmental disability includes but is not limited to severe disabilities attributable to mental retardation, autism, cerebral palsy, epilepsy, spina bifida and other neurological impairments where the above criteria are met (Bill S-1826).

This legislation specifies that, in general, the individual's disability must be manifest before the age of 22. However, a later clause gives the director of the Division discretion in expanding eligibility to any individual under the age of 55 who meets the other criteria if funds allow. Further, a caveat was added so that persons presently being served in the system would be "grandfathered" in without undergoing reassessment according to the new eligibility criteria.

In order to operationalize the definition into eligibility criteria, New Jersey developed a new screening instrument, the Critical Adaptive Behaviors Inventory (CABI). CABI assesses the presence or absence of critical skills in each of the six life activity domains specified in the legislation.

In order to assist in planning and to monitor the transition to a Division of Developmental Disabilities, the Developmental Disabilities Council awarded a grant to the University Affiliated Facility at the University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School. This project is organized around nine task forces focusing on these areas: Intake and eligibility; training; related services; employment; guardianship, advocacy, and self direction; housing; transportation; recodification; and mental health and developmental disabilities. The Year I report from this effort is available. The second year report is due in the winter of 1988. Volume II of the report will focus on task force papers such as: interagency agreements and decisions on staff retraining and reallocation.

Individuals interviewed in the state were reluctant to draw conclusions about the relative success of the transition since the process is still underway. They are anticipating an increased caseload of approximately 460 persons per year with an overall total of from 1500 to 2000 at the end of five years. It is expected that this increased demand will flatten out after some of the pent up demand is accommodated. An increase of 2,000 is anticipated. This is a ball park figure based on the total prevalence of persons with disabilities drawn from census and reduced to 50%, a liberal estimate of how many of these persons are likely to come forward for service. In requesting additional funds from the legislature for these persons, New Jersey applied the appropriate percentage of the total Department of Mental Retardation budget to accommodate 2,000 additional consumers of service.

At present, there has not been a dramatic increase in demand for services. A registry has been created which presently lists several hundred names of new consumers requesting services. The list is expected to grow once the Division is fully operational. A survey of 30 persons on the registry indicates that housing is the service most needed. Housing in this case does not refer to typical group homes, rather it is housing adaptation or alternate living situations that promote independence and have full accessibility. State informants anticipate that the largest consumer group to come forward for service

are persons with physical handicaps who were sorely underserved in New Jersey previously. The second highest need identified in the survey was vocational rehabilitation and the third was transportation.

The anticipated expansion of numbers of persons served in New Jersey is a result of an earnest undertaking to "redirect" service delivery so that persons with all developmental disabilities are indeed served. The redirection of the department has been well advertised and many different advocacy groups have been involved. Consonant with the change in service eligibility, New Jersey is substantially revising intake forms, service assessments and is also expanding and improving their case management system so that case workers have greater understanding of the diverse needs of diverse consumers. Along with a change in numbers of persons served, administrators also expect that the service mix will change (e.g., more emphasis on attendant services, etc.)

The opportunity to include a diverse number of disability types into the service system has encouraged New Jersey administrators to reorient their provision of services to persons having mental retardation. Rather than adopt a "womb to tomb" approach to the new disability consumers, case workers are being trained to adapt to a truly "client driven system" with an emphasis on least restrictive environments, very individualized treatment planning, and provision of the smallest amount of service intervention as possible. Service providers are discovering that small adjustments such as an adaptive devise can ameliorate urgent needs. In like fashion, creative solutions to traditional mental retardation service needs are sought. Although there has been some resistance by non mentally retarded disability groups to come to the division in services, the modest increase in legislative funding allocated and the other efforts of the department described above have helped to alleviate associated stigma.

With respect to the elimination of individuals currently eligible for services, New Jersey interviewees had several observations. First, the new definition will not be used to reassess those currently receiving services. Second, the instrument that has been developed should not screen out anyone in need for services. However, in order to ensure that no one is adversely or unjustly affected by the new definition, the state intends to conduct an evaluation of impact at the end of a year.

B. Ohio

Ohio's Department of Mental Retardation and Developmental Disabilities has been using a categorical definition for service eligibility that included mental retardation, cerebral palsy, epilepsy, and autism. The current definition is limited to these four categories of disabilities, requires that the disability be manifest prior to age 18, requires a substantial handicap, and measures substantial handicap

relative to the abilities of persons with moderate, severe, or profound retardation.

Because of concerns that many individuals with developmental disabilities, other than the four categories specified in the definition, were being unfairly excluded from services, a new definition has been proposed and is currently before the legislature. This definition is similar to the federal definition with the following exceptions: it excludes individuals with a sole diagnosis of mental illness, it includes individuals whose disability is likely to result in substantial functional limitations without intervention (not just those who already have substantial functional limitations), it includes all children under the age of three who have only one developmental delay, it includes children between the ages of three and six who have two developmental delays, and it gives the director of the Office of Mental Retardation and Developmental Disabilities discretion in accepting additional persons for service. Individuals interviewed in Ohio are hopeful that this legislation will pass. They do not expect a dramatic increase in demand for services as a result of the definitional change. In the first place, the legislation does not operationalize eligibility criteria. The Office of Mental Retardation and Developmental Disabilities will define these standards at a later date and it is unlikely that they will set the standards so low that they will admit persons for whom they have no resources. Secondly, current Ohio law authorizes service delivery to certain categories of persons with disabilities. It does not mandate that all eligible persons be served. As a result, OMR/DD has the ability to control the amount of service provided.

C. Maryland

In considering strategies for improving service delivery for persons with disabilities in Maryland, the federal definition of developmental disabilities (PL 98-527) was the first to be evaluated. The full federal definition was not adopted. The major reservation was that the definition did little to operationalize eligibility criteria and left too much ambiguity in the concept of substantial functional impairment. A study conducted by Michael Smull suggested how much variability could be expected given different ways of defining "substantial impairment." Smull and his colleagues conducted a study of 1602 15 year olds who were in special education. They found that different definitions of functional limitation yielded eligibility rates ranging from .57% of the general population to 2.05% of the population.

In July, 1986 the Maryland legislature passed a bill authorizing the Mental Retardation and Developmental Disabilities Administration to adopt a "modified" developmental disabilities definition. This act moved the state from a categorical definition that included mental retardation, cerebral palsy, autism, and epilepsy, to a more functional definition.

Maryland's definition differs from the federal definition in some interesting ways. In the first place, the definition clearly excludes those individuals whose disability results solely from mental illness. These persons will continue to receive services through the state's Mental Hygiene Administration. Secondly, where the federal definition specifies that an individual must be substantially functionally limited in at least three of seven major life activity areas, Maryland's modified definition focuses only on the individual's ability to live independently. This variable is measured in terms of personal and household management and use of community resources. The third, and perhaps most interesting departure from the federal definition involves the establishment of a two-tiered eligibility screen. As noted in the earlier discussion, individuals who meet all criteria specified in the definition (i.e. a diagnosis other than mental illness alone, age of onset before 22, and substantial functional limitation in the ability to live independently) are eligible for the full range of services offered by the state agency.

Those individuals who fail to meet all of the criteria for developmental disabilities may still be eligible for individual support services. To be eligible for the upper tier of services two conditions of disability must still be met. The individual support services for persons with milder limitations do not include full day services and residential services, but include support services focusing on prevention, and enhancing the individual's ability to live independently in the community, some of which may be limited day services and residential supervision.

It is anticipated that this modified definition will, in fact, reduce the number of persons eligible (though not necessarily the actual numbers of persons served) for the full range of services in Maryland. Under the categorical definition, slightly more that 3% of the population were eligible for the full range of services. Under, the new modified definition, only 1.7% are expected to qualify for the full range of services. Individuals who would have qualified under the old definition will remain eligible for individual support services, but will not be eligible for full day and residential services. A grandfather clause in the legislation protects the eligibility status of people already in the service system.

Despite overall reduced numbers of persons eligible for service, the adoption of the functional definition has opened doors of service to low incidence disability groups, and consequently a waiting list of 2,000 persons with disabilities other than mental retardation has been formed in Maryland. Needs assessments have been conducted by Morrison, Sachs & Smull (1886) on the persons on the waiting list. The waiting list represents the best information known to project staff on the numbers of persons with disabilities other than mental retardation that will actually come forward for service, given changed service eligibility, and what their service needs are. The data from the survey of the waiting list forms the basis of the projected demand of service

anticipated in Connecticut and outlined in Section V. However, Maryland researchers advise to view this data as an underestimate of the total numbers of persons with disabilities other than mental retardation that may come forward for service. They explain that limited funds and a limited service array discourage many potential consumers from identifying themselves for service.

D. Hawaii

In 1983, Hawaii changed from a categorical definition of disabilities that included mental retardation, epilepsy, autism and cerebral palsy to the federal definition of developmental disabilities. Any persons eligible for services under the old categorical definition were automatically eligible for services under the new definition. However, it is anticipated that individuals with similar levels of disability will be screened out in future years.

Interviewees in Hawaii said that they had anticipated an increase in demand for services as a result of this change. However, to date, there has not been a dramatic increase in the amount of service provided. Two reasons are cited to explain this. In the first place, the change in eligibility was not advertised widely. Secondly, the Hawaii statute does not mandate that all service applicants be served. The department operates within a budget and provides services only within its means. If new resources are not allocated, new services will not be developed.

The most noticeable change has occurred in the area of case management. Since the state agency is now dealing with more individuals having more complex physical disabilities, case managers have had to adapt their strategies and reach out to different types of service providers.

Currently, the state is attempting to operationalize eligibility criteria and to develop an instrument for assessing substantial impairment in three of the seven major life activities specified in the federal definition. They are also working on due process and grievance procedures for persons who are determined to be ineligible for services under the federal definition.

E. California

California considered adopting a functional definition for developmental disabilities in the early 1980's. The Health and Welfare Agency contracted with Berkeley Planning Associates (BPA) to explore the implications of making this change. As noted above, the BPA study described alternative organizational arrangements that were possible for the state to consider and summarized data on prevalence rates for

various disabilities using both the federal definition of developmental disabilities and the categorical definition employed in California. On the basis of data from the 1976 Survey of Income and Education, BPA concluded that the transition to the federal definition might mean that as many as four times as many individuals would become eligible for services. On the basis of these projections and their assessment of the current service delivery system in the state, California officials decided against the federal definition and kept the categorical definition that included mental retardation, cerebral palsy, epilepsy and autism.

Interviewees in the state do not feel that there are substantial numbers of individuals who are unserved. They believe that those persons who do not meet the eligibility criteria of their categorical definition are receiving services through other state agencies.

F. Lessons from Other States

The review of issues arising in other states includes some important guidelines for any changes in Connecticut, including the following:

1. Based on the Hawaii experience, changes in agency mandates tend to have an immediate impact on case managers who must reach out to different groups and learn different service systems and providers.

2. The Ohio experience illuminates a way to focus attention on persons with severe disabilities while also recognizing the support needs of persons with more moderate disabilities. By including a section in the definition that allows eligibility for persons who would develop severe limitations in the absence of intervention. Maryland's "two tier" approach is also a response to assuring persons with less severe disabilities receive needed support.

3. The New Jersey review reinforces the necessity to build in periodic evaluation in order to ensure that the application of a new definition does not unduly penalize any particular disability group. New Jersey's three year phase-in is also a useful way of ensuring orderly implementation.

4. The review of changes in Hawaii's system reinforces the importance of developing a grievance mechanism to ensure the any definitional changes do not result in unjust service exclusion.

5. The New Jersey and Maryland reviews draw attention to the necessity to develop instruments that are capable of discriminating among those who are eligible and those who are not eligible for services.

Unfortunately, the review of other state experience does not shed light on system reforms that implicate multi-agency changes such as those contemplated by this project.

V. PROPOSED RECOMMENDATIONS

The main mission of this project was to determine whether it is feasible to expand the mission of the Department of Mental Retardation to include services to individuals with other disabilities. The general conclusion of the analysis is that such a change is feasible. HSRI, however, has concluded that this change alone will not ameliorate the problems facing individuals with disabilities in Connecticut. No one agency is capable of meeting all of the needs of persons with disabilities or even of a subset of such individuals. What is needed is a system that:

- Has well-defined entry points for the provision of services to meet specified needs;
- Is connected at multiple junctions through formal and informal coordinated mechanisms;
- Is "multiply permeable" (i.e., is open to the entry of disabled persons at multiple locations) not at a "single entry point;"
- Recognizes the needs of persons with moderate and mild disabilities for periodic support and assistance as well as the need of persons with severe disabilities;
- Is based on individual needs and capabilities, not on categorical labels;
- Recognizes the critical role played by generic agencies, such as housing and transportation, in meeting the needs of persons with disabilities;
- Maximizes the input of persons with disabilities.

With respect to a Department of Developmental Disabilities, HSRI recommends that the eligible population be expanded to include: a) persons with severe disabilities; who b) have a need for ongoing supervision and support; and c) can benefit from the array of services available in the Department of Developmental Disabilities (e.g., supported work, supervised residential, specialized therapies, intensive case management, etc.).

A. Service Principles

Any change in the service system for persons with disabilities in Connecticut should further an overall policy agenda based on a set of agreed upon principles. The following statements reflect programmatic aims that should govern the delivery of services by every relevant state agency.

- Access to services should not be denied to anyone on the basis of his or her disability;
- A priority should be placed on those most in need of services;
- Maximal outreach effort should be made to ensure that persons with disabilities are aware of service availability;
- All persons applying for services should be treated with dignity and sensitivity to their special needs;
- Information regarding the availability of other services should be made available to persons with disabilities;
- The process of applying for services should be made accessible to people with a range of disabilities.

B. Outline of System Reorganization

In order to structure the recommendations, the common service needs among people with disabilities have been divided into four categories: generic services (transportation, income support, etc.), enabling services (case management, information and referral), specialized/therapeutic services (residential, training, vocational), and advocacy.

1. Generic Services

With respect to generic services, there was substantial discussion during the course of HSRI's interviews regarding problems encountered by people with disabilities in securing services such as transportation and housing. Several problems were noted including the adequacy of available services, the sensitivity of agency personnel to the needs and feelings of persons with disabilities (e.g., treatment of families applying for the Model 50 waiver program), and the exclusion of certain

persons with disabilities from service eligibility (e.g., persons with mental health problems in public housing). To overcome these problems, there is a need to adopt the principles noted above within each agency in the state.

There are several ways in which these principles should be institutionalized across state agencies:

1. Strong statement of legislative intent;

2. Gubernatorial directive;

3. Adoption by the Human Services Cabinet;

4. Training agency personnel;

5. Embodiment in quality assurance standards;

6. Ongoing advocacy.

In order to ensure that these principles are in fact operationalized within generic agencies, HSRI suggests that the Connecticut Developmental Disabilities Council be given the responsibility to conduct yearly audits through consumer surveys, public forums, review of agency records, and reviews of advocacy interventions.

2. Case Management and Enabling Services

This category of services includes the following components:

- information and referral;
- counseling and brokering of generic services;
- program monitoring;
- follow-along;
- crisis intervention;

- program development and program planning;

- advocacy on behalf of the client.

The level and intensity of these services depends on the needs of the person with a disability at a particular point in time. A person with severe multiple disabilities may need case management and enabling services on a continuing basis and may require the full range of service components. An individual with a serious physical disability but no congnitive or emotional problems may require only periodic case management assistance or information and referral services. An individual with a learning disability may not require continual case management but may need someone to periodically check and to be available in times of personal crisis (e.g., loss of job, apartment, etc.).

Given this diverse picture of case management needs among persons with disabilities, the following multiple recommendations are made:

1. The Department of Developmental Disabilities should have the responsibility for the provision of case management to those individuals with severe disabilities who require long-term supervision and support;

2. The Department of Human Resources should be given explicit responsibility for case management for those individuals with severe disabilities who have periodic support needs and who are capable of self-direction;

3. An expanded network of independent living centers should (in addition to their other mandated responsibilities) be responsible for providing ongoing support and assistance to individuals with milder disabilities;

4. The Department of Health Services should be responsible for case management for families qualifying for the Medicaid Model 50 (Katie Beckett) waiver;

5. The Department of Mental Health should be responsible for providing case management for persons with severe psychiatric disabilities who need ongoing assistance and support.

Recommendation #1 does not require any substantive change in the content of case management services currently being provided by the Department of Mental Retardation, but will involve an increase in the

individuals eligible for such services. Recommendation #2 will necessitate the formalization of the case management function currently carried out informally at the Department of Human Resources. Recommendation #3 will require a substantial increase in the availability of independent living services statewide and the expansion of independent living services to include a follow-along responsibility for persons with mild to moderate disabilities who need periodic oversight and crisis intervention.

Recommendation #4 would entail the movement of the Medicaid Model 50 waiver program from the Department of Income Maintenance to the Department of Health Services. Such a move would place the program in an agency with more background in children's health issues and in the needs of families with chronically ill children. Recommendation #5 is a formal reiteration of current state policy.

3. Specialized and Therapeutic Services

In addition to generic services and case management, people with disabilities also require specialized services to meet their disability-specific needs. Some of these services include:

1. Physical and occupational therapy;
2. Job training, supported work and job placement;
3. Adaptive equipment and adapted living and work environments;
4. Independent and personal living skills training;
5. Attendant services;
6. Residential arrangements;
7. Family support services (e.g., respite);
8. Behavior management;
9. Psychiatric care and treatment.

Again, given the multiple needs and service preferences of persons

with disabilities, the following recommendations are made:

1. The Department of Developmental Disabilities should provide a full array of services (residential, training, supported employment, etc.) to individuals with severe disabilities who have long-term needs for care and support potentially included persons with severe cerebral palsy and traumatic brain injury.

2. The Department of Human Resources should be responsible for the provision of attendant and essential services (e.g., homemaker/chore, home adaptation);

3. The Department of Mental Health should be responsible for the provision of a full range of services to persons with severe psychiatric disabilities;

4. The Parent Subsidy Aid Act should be reshaped and should be turned into a direct family subsidy such as that currently in place in Michigan. The new subsidy program should be administered by the Department of Health Services.

Recommendations #1-#3 require no substantive change in services but do, in the case of Recommendation #1 specifically, imply an increase in the target population. The initiation of recommendation #4 will require a substantive change in emphasis in the provisions of the Parent Subsidy Act and the development of revised statutory requirements. The move of the program to the Department of Health Services will centralize support (other than educational services) to children with chronic illnesses and disabilities.

4. Advocacy

One of the major complaints made by consumers of services who were either interviewed as part of the project or who attended the public forums was the arbitrary exclusion from services because of categorical requirements. The movement to a functional approach to the provision of services in the state will not necessarily be self-enforcing and will need to be backed up by an external grievance mechanism. HSRI therefore recommends the creation of an independent complaint mechanism attached to the new Office on Policy Affecting Persons with Disabilities (described below). The purpose of the new advocacy entity would be to review instances in which individuals were denied services by a state agency or were not given an appropriate service level or type.

5. Policy-Making and Coordination

One of the remaining issues to be addressed -- and one that has been raised by other studies as discussed in Section III -- is where will policy on behalf of persons with disabilities be generated and coordinated? To respond to this concern, HSRI is recommending the creation of an Office on Policies Affecting People with Disabilities. The responsibilities of this agency would include the following:

1. Prepare yearly reports on priorities for service development;

2. Identify gaps in services;

3. Assess unmet needs, and maintain an index of demand for services;

4. Propose any new legislation;

5. Convene meetings;

6. Prepare reports on cross-dimensional issues (e.g., integration, supported work, etc.);

7. Ensure that adequate training is provided to staff of generic and specialized agencies;

8. Report to the Governor and the Legislature.

The Office of Policy Affecting Persons with Disabilities should reflect concerns for all persons with disabilities and should be as autonomous as possible. To achieve its consumer-based mission, the Office should be tied directly to an advisory committee made up of persons with disabilities.

In order to avoid the creation of an entirely new agency, HSRI is recommending that the new office be made APO (administrative purposes only) to the Department of Human Resources. The selection of the new director of the office should be a participatory process that involves the advisory committee noted above. While it is clear that there is a good deal of support for the establishment of such an office in the Department of Human Resources, project staff felt strongly that for symbolic as well as substantive reasons, the office should enjoy a certain amount of autonomy -- especially if it is to reflect the

interests of all individuals with disabilities and to have standing with the range of other state agencies whose programs can benefit persons with disabilities. If a decision is ultimately made to place such an office in an existing state agency, it is strongly recommended that a consumer advisory board play a substantial role in determining the ongoing directions and priorities for such an entity.

6. Independent Living and the Division of Rehabilitation Services

HSRI's recommendations place substantial weight on the role of Independent Living Centers (ILCs) in the state. Specifically, the ILCs will serve as a place where all individuals with disabilities can receive information about the services available to them. We also propose that the centers provide continuity and assistance to individuals with milder disabilities. Given these significant responsibilities, it would be a mistake to separate the administrative responsibilities of any new state-funded centers from that of the two federally-funded centers already in place. Keeping the programs together will also enhance the ability of the state to maximize the use of additional federal independent living funds in subsequent years.

In determining how to structure the future of the independent living program, it is important to review the federal guidelines. Independent Living Centers are administered through the Federal Rehabilitation Services Administration. Each state can apply for grants to operate ILCs. However, the state vocational rehabilitation program has first priority in receiving and administering state grant monies. State vocational rehabilitation agencies have a certain time limit by which they must indicate their interest in operating the centers. If they do not express interest, other state agencies and private vendors can submit proposals for a center. Nearly all state vocational rehabilitation programs have opted to run the program, as is the case in Connecticut. However, once a state vocational rehabilitation agency is operating the program, it is possible to transfer the administration directly to the private vendors that have been providing independent living services. Two centers in Nevada and Hawaii have received direct administrative responsibilities.

The issues surrounding the independent living centers have direct bearing on issues affecting the Division of Rehabilitation Services. While this project did not focus specifically on the future of DRS, HSRI does suggest some specific criteria that can be applied in arriving at a decision.

1. Will it renew the mission and vision of the vocational rehabilitation program?

2. Will it ensure that the vocational rehabilitation program employs approaches that reflect the state-of-the-art in work-related programs for persons with disabilities?

3. Will it recapture consumer credibility in the agency?

4. Will it assure accountability for the outcomes of services?

5. Will it assure that the organizational structure is capable of accommodating and facilitating the future development of rehabilitation and independent living services.

In reviewing the options, it should be kept in mind that the vocational rehabilitation movement nationally as well as in Connecticut is going through substantial changes in ideology and practice. The vocational rehabilitation program is one of the first progressive human services programs in the country and comes out of the "New Deal" tradition. At its inception it was a pioneering effort. Such dynamism is difficult to maintain over decades of service delivery. The program is currently going through an agonizing reappraisal and reorientation and such change does not come without cost and stress. With these stresses in mind, any solution that is developed should facilitate rather than hinder this transistion.

One possible solution is the placement of DRS and the independent living program under the Office of Policy recommended above. Such a move has the virtue of renewal and should recapture consumer credibility given the direct association of the office with a participatory consumer advisory body. The organizational structure should also give DRS the flexibility to initiate change and to be responsive for changing consumer expectations.

The other option that has been suggested is movement to the Department of Human Resources. Such a choice should also bring about a renewal but without the concomitant development of an autonomous consumer advisory body, the ability of the reconstituted agency to change and develop with the state-of-the-art may not change appreciably.

C. Implications

1. Demand of services

a. Impact of definitional changes in service eligibility according to selected studies.

The changes proposed above will clearly have an impact on the magnitude of services provided in Connecticut. The purpose of this section is to review the impact of changes in the definition of eligibility for services, in other states in order to anticipate such changes in the volume of demand. This section relies on written reports from California, Florida, New York, Maryland, Ohio. All of were aimed at the development of estimates of the impact of implementing various forms of the so-called "functional definition" used in the federal Developmental Disabilities Act.

Each of the above studies relied on different data bases and targeted different potential outcomes of definitional changes. In order to appreciate the common elements among the studies, it is useful to present some common conceptual definitions.

- ***Prevalence of developmental disabilities.*** The California, Florida and Ohio studies base their analyses on estimates of prevalence. Prevalence refers to the number of person who at a given time, have a developmental disability.

- ***Service utilization or expressed demand for service.*** This concept refers to persons who are presently receiving services, have requested services, or are otherwise known to service agencies. The expressed demand for service is almost always a portion of the total prevalence of a given condition. The Florida and California studies, in part, contrasted total prevalence of developmental disabilities with the expressed demand for services.

- ***Unexpressed or potential demand.*** This refers to the difference between the projected prevalence of a given condition and the numbers of persons who are actually receiving or are requesting services. These are percentages of persons who are assumed to have a developmental disability, but have not "come forward" to request services. Depending on eligibility criteria, and other factors, the persons who potentially may need services may never come forward. Expectations about increased service demand often center around assumptions regarding the percentage of unexpressed demand for services that is expected to apply for services.

- ***Newly eligible for services.*** This refers to persons who were not eligible for developmental disabilities services using a categorical definition, but who, given a functionally based criteria, would become eligible for such services. This term often implies persons with low incidence disabilities, such as spina bifida or head injury. Persons who become newly eligible for developmental disability services may or may not be already receiving services through another agency. All of the studies assessed the potential impact of a switch to a functional definition, on persons presently being served in one or more state agency. The Maryland study also assessed impact on a "waiting list" of persons presently unserved.

The studies reviewed for the Connecticut project can be briefly summarized as follows:

- A study based on California data projected a developmental disabilities prevalence of 1.17%. The study also projected a fourfold increase in the numbers of persons potentially eligible for services. According to the report, the majority of those deemed newly eligible were already receiving services in one or more California agency. The study did not project how many persons newly eligible, but not receiving services, would request services. Barker, L.T., & Kogan, D. (June 1983). Study of the Federal Definition of Developmental Disability. Vol.I: Summary of Findings. Berkeley, CA: Berkeley Planning Associates.

- A Florida study projected less than 1% prevalence of developmental disabilities. Of those defined as developmentally disabled, 77.1% were already served in one or more state program. Increased demand for service was anticipated to come from groups who were presently known to the service system but were underserved. Brehon Institute. (June 1985). Whom shall we serve? A policy study on the application of a functional definition of developmental disabilities in seven Florida programs. Tallahassee, FL: Brehon Institute.

- The authors of this study found that application of functionally-based eligibility criteria to persons presently receiving services in New York, would reduce the numbers of persons eligible for service in each categorical disability. However, the majority of persons would remain eligible. Lubin, R., J.W. Jacobson, M. Kiely. (1982). Projected impact of the functional definition of developmental disabilities: The categorically disabled population and service eligibility. American Journal of Mental Deficiency, 87,(1), 1982, 73-79.

- Studies in Maryland concluded that substantial numbers of

persons receiving services in the community, or on waiting lists, would become ineligible for service depending on the strictness of the interpretation of functional limitations. Morrison, L.M,. Smull, M. & Sachs, M. (September 1984). Adopting the federal definition of developmental disability: A preliminary analysis of potential effects on eligibility. Baltimore, MD: University of Maryland, School of Medicine.

- Studies in Ohio indicated that most persons with developmental disabilities who were not retarded were eligible for services. Ohio concluded that the numbers of people to be served or planned for would remain relatively stable but that the nature of the population and the constellation of needs they represent will change. Ohio Developmental Disabilities Planning Council. (December 1986). Fiscal implications of adapting the definition of developmental disability as proposed by the Ohio Developmental Disabilities Planning Council. Columbus, OH: Ohio Developmental Disabilities Planning Council.

Before proceeding with a detailed summary of the studies, it is important to keep the following points in mind:

- Planners are ill-advised to assess the impact on potential demand for services by merely reviewing estimates of prevalence alone. There is no established relationship between prevalence and expressed demand for service. In general, a large number of persons with mental retardation and other disabilities never express a demand for service.

- The actual expressed demand for service is as much an expression of the "supply" of service as the demand. That is, demand is related to eligibility requirements, and to the types and amounts of services made available. It is quite difficult to compare service utilization rates and the potential impact of new eligibility criteria across states without an understanding of these confounding variables.

- Prevalence data drawn from the 1976 Survey of Income and Education (which form the basis for many of the prevalence estimates in the above studies) need to be viewed with caution for the following reasons:

  -- the standard error of the SIE for prevalence of developmental disabilities is too high to use this data unchecked. This is due to the relatively low incidence and low sample size for developmental disabilities;

-- the prevalence rates for mental retardation are confined to the noninstitutionalized population. In addition, household surveys may also underestimate the prevalence of disabilities because of the perceived stigma;

-- the survey does not cover infants and children under age three;

-- the prevalence of developmental disabilities other than mental retardation are judged to be artificially high because criteria used are not sufficient to screen out some less severely disabled persons.

- In general the overall prevalence of groups assumed to become newly eligible for services given a functional definition, is only a fraction of the larger group, predominantly persons with mental retardation, who are currently eligible for service. Therefore, a significant net change in the numbers of persons to be served or planned for is not likely. However, newly eligible groups are likely to require different and potentially more expensive services than do the predominant consumers of developmental disability services today -- persons with mental retardation.

b. Review of Selected Studies

1) California

The California researchers operationalized concepts of substantial functional impairment in major life activities (based on the work of Elinor Gollay, 1980) and prepared separate case review instruments for each of five California state agencies in order to estimate the prevalence of developmental disabilities and levels of service utilization.

Using California specific data in the 1976 Survey of Income and Education, a prevalence rate of 1.17% was found for persons meeting a functionally based definition of developmental disabilities. Interestingly, using Gollay's indicators, 44% of emotionally disturbed individuals could be identified as developmentally disabled and only 2% - 10% of those reporting a physical handicap were deemed to be developmentally disabled.

The authors proceeded to determine what portion of persons currently served in each of five California service agencies would be considered to be developmentally disabled according to the federal definition.

Utilizing case review data from five agencies, the proportion of clients who would meet a revised definition of developmental disabilities would increase as follows: 1) 11-14% in Children Services (Title V agency); 2) 20-23% in In-Home Supportive Services; 3) 3-34% in Special Education; and, 4) 4-15% in Vocational Rehabilitation. A 3-7% drop in the percentage of persons meeting the functional developmental disability definition was estimated for the California Regional Center System.

These data suggested that a substantial number of persons would become newly eligible for developmental disability services. However, the study concluded that a majority of these individuals were already being served by one or more California agency.

Even though the majority of individuals who fell into the functional definition of developmental disabilities were already receiving some services, the authors noted that a substantial number were still unserved. They do not estimate what percentage of this group would come forward to demand service from a developmental disability agency. Given the unreliability of prevalence data in predicting service demand, the conclusions are unsatisfying and the projected impact is probably too high.

The report concludes that a change in the definition would result in an increased number of eligible individuals, that the largest segment of the total eligible population would be persons with physical handicaps, and that the majority of these individuals are already receiving services from one or more state agencies (but not necessarily the regional centers).

2) Florida

The Florida study assessed the impact of changing to a functional definition of developmental disabilities for the State of Florida as a whole and for seven Florida public service agencies. Using Florida data from the 1976 Survey of Income and Education, investigators applied a functional definition of developmental disabilities, and used synthetic estimates to project a prevalence of less than 1% of persons with developmental disabilities in Florida in 1985.

Random case reviews of records in seven Broward County agencies (Special Education; Education - Division of Blind Services; Developmental Services; Childrens' Medical Services; Vocational Rehabilitation, Adult and Aging, Children, Youth and Families) were conducted. Each case was drawn from a list of persons who potentially had a developmental disability, and was then reviewed for substantial limitations in three out of seven major life activities. Case review data was used to estimate an unduplicated count of persons with developmental disabilities currently in the service system. The results

showed that 77.1% of the total projected number of persons eligible for developmental disability services were participating in one or more state program. Service status for the remaining 22.9% was unknown.

A review of case records of persons with mental retardation served by developmental services in Broward County showed that 1.9% did not meet criteria for developmental disability. Similarly, about 5% of persons having cerebral palsy as a primary diagnoses failed to show the requisite number of substantial functional limitations for inclusion into the developmental disability group. Inconsistent data was found regarding the functional limitations of persons with epilepsy. However, a parameter of 19.6% of the epilepsy caseload was used as an estimate for numbers of persons with epilepsy also having developmental disabilities. A greater demand for services is projected to come from persons who are presently served in only one or two state programs, but who would become eligible for developmental disability services if a functional definition were adopted. Other increased demand is expected to come from the previously unserved and unidentifed persons who would become eligible for services in Florida (22.9%). How many of these persons may demand services is not projected.

Individual case profiles revealed that the population encompassed within the functional definition consists of five groups, each group having a separate and distinct pattern of disability and service needs: 1) accident victims between age five and 22, resulting in substantial neurological damage; 2)persons suffering degenerative diseases; 3) persons with chronic, severe psychosis occurring before age 22; 4) persons with conditions placing them at risk of severe disability who improve or whose disabilities are ameliorated through early intervention; and, 5) persons with conditions occurring in the first five years which prevent or interrupt normal developmental processes. A department of developmental disability may not be appropriately funded, mandated or have sufficient experience to serve this diverse range of needs.

3) New York

Indicators of substantial functional limitation were drawn from a New York statewide needs assessment/adaptive behavior measure and applied to the New York State Developmental Disabilities Information System. This was a data-base of the characteristics of 38,000 clients receiving developmental disabilities services in New York State. Results were obtained across 11 different disability categories and four age categories. For adults, the following are the percentages of persons with "categorical" disabilities who had limitations in three or more life activity areas: 1) mental retardation - 73.3%; 2) autism - 53.1%; 3) cerebral palsy - 55.6%; 4) epilepsy - 35.4%; 4) neurological impairment - 30.6%. Persons with two or more categorical disabilities ranged from 52.9% (cerebral palsy and epilepsy) to 94.9%. These figures differ significantly from the percentages reported in the Florida study

above. The report concludes that most persons presently served would continue to be eligible under a functional definition. Likelihood of impairment was found to vary as a function of disability type, age, and I.Q.

4) Maryland

The first Maryland study examined four data bases in order to determine the potential impact of switching to a functional definition. The four data bases included: 1) the Client Based Information System (CBIS) which contains demographic and functional information on 5,442 persons served by the Maryland Mental Retardation/Developmental Disability Administration. This group is divided into community-based and institutional clients; 2) the Mental Retardation Community Needs Survey (MR CNS) which contains data on persons with mental retardation, who are living at home and are currently in need of services but are not receiving them. There are presently data on 2,152 individuals who were referred to the survey through various sources; 3) the Non Retarded Developmentally Disabled Community Needs Survey (NRDD CNS) contains information on similar community members who do not have mental retardation.

The study team devised operational criteria to determine for each data base whether a client would meet substantial limitations in three out of seven major life activities. The criteria were based on the operational guidelines prepared by Gollay (1980) (see note 1). However, because the data-bases were not designed specifically to ascertain limitations in all seven of the major life activities, some of the life activity areas were not assessed comprehensively and may have led to inaccuracies in determining the presence of substantial functional limitations. The authors therefore advise caution in interpreting some of the findings.

The findings of the study are as follows:

- 94% of institutional clients would be eligible for services under the federal definition;
- 49% of clients currently served in the community would continue to be eligible;
- 54% of clients with retardation in the community but not receiving services would be eligible;
- 24% of clients without retardation in the community, who showed age of onset of functional limitation after age 21 (65% of the

data-base) and identified as being in need of service, would be eligible.

The authors also applied a Health Care Financing Administration interpretation of the federal definition. This interpretation is used to determine eligibility for ICF-MR services. It differs from the federal definition by excluding "economic self-sufficiency" as one of the seven possible major life activities. It requires instead, substantial functional limitation in three out of six of the remaining major life activities. As this is a more strict interpretation, correspondingly fewer persons were deemed eligible.

When partial limitations (which represent an intermediate degree of impairment) were included in the determination of substantial impairment in major life activities, the percentage of persons deemed eligible for developmental disability services in each data base increased as follows:

- 100% of institutionally served clients
- 91% of community served clients
- 70% of community clients not served with mental retardation
- 59% of community clients not served having normal intelligence.

Data is also presented identifying which groups, with which types of categorical disabilities most frequently have functional limitations.

The authors conclude that implementation of the functional definition would reduce the numbers of eligible persons, consistent with the expressed intention of the definition (i.e. to focus resources on the more severely impaired). The authors recommend that Maryland has to consider carefully which persons with disability they wish to serve. If the state wishes to serve those persons who may be excluded by the federal definition, but are other wise still in need of some services, then different eligibility criteria would have to be devised.

Michael Smull and others at the University of Maryland conducted other unpublished studies pertaining to the impact on eligibility of the implementation of a functional definition of developmental disabilities.

Information was collected on 1,602 15-year-olds identified in special education (a 50% sample of students in levels 3-7 in 9 local

education areas). Detailed information was collected on the seven life activity areas. Results indicated that the prevalence of persons eligible for services would range from .57% to 2.05 % depending upon how strictly the interpretation of functional limitation is used.

Under the presently proposed definition of developmental disability in Maryland, (using two tiers of service eligibility: one for persons who are developmentally disabled according to the federal definition, and one for persons who meet only some of the criteria specified in the definition) the total number eligible is estimated at 1.7% of the total state population. Less than half of these persons are presently known to the service system, and the authors anticipate that the total numbers of persons served would not change given new eligibility criteria.

The new criteria would change the federal definition of developmental disability in one important aspect -- rather than requiring impairment in three of seven life activity areas, the proposed definition focuses limitations in only one life activity area, the ability to live independently without external supports. Researchers applied this criterion to 800 persons receiving and awaiting services and found that 85% of community-based clients presently served would continue to be eligible and that 15% would be eligible for the upper tier of "individual support services." (This upper tier does not include residential or day services). In addition, 75% of those waiting for services who have mental retardation would be eligible for services, and 49% of persons waiting for services without having retardation would be eligible for services. (These percentages are higher than the ones estimated in the preceding study, reflecting the more liberal interpretation of developmental disability proposed).

5) Ohio

The Ohio study estimated service demand and associated costs given utilization of a proposed functional definition of developmental disabilities. (This definition excluded those persons determined to be disabled solely because of mental illness). The authors used published data regarding the prevalence of categorically defined developmental disabilities. Subsequently, published data was used to ascertain the number of persons with specific disabilities who are also estimated to be either developmentally disabled or mentally retarded. These persons were presumed to be presently served.

Service needs were then approximated for those persons who would have a categorical disability and would be considered to be developmentally disabled, but do not have mental retardation. These persons were assumed to represent the numbers of persons who would be eligible for services but who are not presently being served in the system. Cost estimates did not include estimates for persons with low incidence disabilities. There is no firm data on how many of these

persons would be considered to be developmentally disabled (given age of onset requirements and whether the disability would be lifelong). Further, the authors assume that such persons are unlikely to seek services from a developmental disability agency. Data is presented on estimated service costs based on current service costs in Ohio. The report concludes there will be little impact on the actual number of persons to served or planned for. Of greater significance is the likely change in the types of disabilities served, and the constellation of service needs that these disabilities represent.

c. Conclusions

1) In general, all studies indicate that the majority of persons presently receiving and eligible for services, would remain eligible for services. There is variance in the percentage of persons presently receiving services who would be excluded from service given a functional definition.

2) Of those persons who would become newly eligible for services, several states indicated that the majority of those persons are already being served in one or more state agency. This raises the difficult policy question of whether services for such persons should be transferred to a developmental disability agency. It is uncertain whether these persons are receiving adequate services in their present agency. Further, it is unclear whether, given eligibility for developmental disability services, they would request additional services, and whether a developmental disability agency is equipped to handle the diverse needs of newly eligible consumer groups.

3) All of the researchers (except for Smull et al. in Maryland) were unable to predict how many persons made newly eligible for services, but presently not receiving services would come forward for services. Given the reluctance of persons with physical disabilities to seek services from an agency associated with, mental retardation, it may be assumed that demand for services among persons presently outside of the service system will not be substantially increased. This assumption is fortified by the knowledge that the overall numbers of persons in the low incidence disability groups who have substantial functional limitations is very small in relation to the numbers of persons who would remain eligible for developmental disability services.

4) Maryland data indicate that there are substantial numbers of persons, presently unserved, but who are identified as needing services, who would become ineligible for services under a functional definition. Therefore, adopting the federal definition requires an assessment of service priorities. Without careful consideration, state planners may end up excluding

numerous persons, who while not presenting severe handicaps, nonetheless do present significant needs for service. An example can be drawn from persons with epilepsy, who may not show numerous functional limitations, but who do require counseling and support.

5) Several of the studies emphasize that while a change in the total numbers of persons served is not anticipated, planners can anticipate a change in the types of disability that would fall under a developmental disability agency mandate. A developmental disability agency may or may not have the expertise, funding options, or service arrays to enhance the well-being of groups of persons with very disparate needs.

6) Unpublished data from Maryland indicate that the total numbers of persons eligible for services will fluctuate widely according to how strictly one interprets the federal definition. All studies used the definition as operationalized by Elinor Gollay, however any number of other interpretations can be made. Of particular concern is the age of onset criterion, which can be perceived as an arbitrary cut-off for eligibility. Given the fluidity by which the federal definition can be interpreted, it appears that any given state would have to develop their own operational criteria and instrument to assess developmental disabilities. This can be a costly and time consuming operation.

7) Finally, it must be remembered that the federal definition is proposed as a planning tool to help direct funding and research activities to persons with more severe impairments. Operationalizing the definition into eligibility criteria may be inappropriate.

Clearly, numerous researchers and state planners have attempted to understand the application of the federal definition of developmental disabilities to actual state service delivery contexts. The results, however, are somewhat inconclusive. Most of the studies project an increase in potentially eligible clients, and one study projects a decrease. None focus on the extent to which those persons who are unserved would demand additional services under an expanded definition, and how many of those outside the system would come forward.

Given the indeterminant character of potential demand for new or expanded services, other factors have to be taken into account when developing impact estimates. These factors include the proposed range of services to be provided, the quality of services, the extent of outreach and publicity associated with service offerings, and the ways in which the definition is operationalized.

What also emerges from this overview is that the federal definition was never intended to govern service eligibility at the delivery level. It was intended to focus planning and funding activities on individuals most in need and to facilitate further coordination between agencies in the development of comprehensive services. Without specific indicators and instruments to accompany the outlines of the definition, its application is ambiguous and somewhat unreliable.

The review of research also raises the question of the potential exclusion of individuals currently receiving services. Without any additional embellishment, the federal definition does eliminate persons with less severe disabilities who may in fact require services in order to maximize functioning and well-being. These issues have been addressed in our recommendations to Connecticut.

Finally, the studies tend to reinforce the disparate groups encompassed within the definition and the range of needs that they present. Persons with physical disabilities, persons with brain injury, persons with severe learning disabilities, people with terminal and debilitating conditions -- all require services which do not neatly fall within one agency.

2. Estimated Increased Service Demand by Service Agency

a. Department of Mental Retardation

As proposed, the Department of Developmental Disabilities can expect increased demand from consumers who have disabilities other than mental retardation and who have severe functional limitations requiring ongoing residential and vocational support. One approach to determining the demand that can be expected by an expanded department, would be to ascertain the prevalence of individuals in Connecticut with disabling conditions who have severe functional limitations. However, as explained in the previous section this would lead to a highly inflated number since research consistently shows that the actual expressed demand for service is far lower than the prevalence of the condition, and is instead tied to the kinds and amounts of services offered.

As there is no reliable data or method by which to determine the potential expressed demand for service among persons having developmental disabilities other than mental retardation, HSRI turned to the limited data that is available. Morrison, Smull, and Sachs (1984) conducted a survey of persons with developmental disabilities other than mental retardation who are living in the community. The survey data constitutes a waiting list for services. The survey form was distributed to persons identified by advocacy groups, provider agencies, and local service departments throughout Maryland. The survey form continues to be distributed and each year new persons are added to the

data base. The survey form ascertains functional limitations according to the federal definition and also requests age of onset information, along with service needs. As of 1986 there are 1391 adult respondents to the survey who meet the Maryland "two-tier" definition of eligibility criteria. This represents the most comprehensive listing of persons with developmental disabilities other than mental retardation who are likely to express a demand for service, and is used as the basis for estimating future demand in Connecticut.

There are certain limitations to the Maryland data base. Though it is the most comprehensive list presently known to the Institute, the Maryland researchers advise that the numbers are still likely to be underestimates of potential expressed demand. The limited funds and limited service array in Maryland discourages persons from filling out the survey form. In addition, the service conditions of each state are unique resulting in differing rates of service utilization and service demand. Nonetheless, any indication of potential demand, even an underestimate, is better than presenting overwhelmingly high prevalence data. Further, Connecticut and Maryland share certain features such as similar state population sizes, similar rural/urban mix, and geographical proximity. Further, a review of the types of disabilities identified in the Maryland data indicate that the largest groups of disability types likely to come forward for service have been identified (i.e. cerebral palsy, head injury, multiple sclerosis, and epilepsy).

Extrapolating the number of total adults identified in the Maryland data to the state population of adults over age 20 (n=3,017,000) gives a .0461% demand rate. Applying this rate to the adult Connecticut population over age 20 (n=2,317,000) equals 1,068 persons. Based on an analysis of survey questionnaires the Maryland researchers project that of this figure 61% would be eligible for Tier One services, which are the same services proposed for the Connecticut Department of Developmental Disabilities. Sixty-one percent of 1,068 is 651.

Although 651 is a reliable figure with which to estimate the growth of the Department of Developmental Disabilities, it does not include those persons who may manifest severe functional limitations *after* age 22, because the Maryland eligibility definition does not include these persons. In accordance with the recommendations proposed here, this figure must be amplified by those number of persons who will manifest severe functional limitation after age 22. The most significant group of persons likely to manifest severe functional limitations is the traumatically brain injured (TBI). The base figure of 651 is amplified to reflect TBI in the following manner.

A study conducted by the Connecticut Traumatic Brain Injury Association (1985) shows an incidence rate of traumatic brain injury in Connecticut to be 152 per 100,000 based on hospital records. Applied to the adult population, this yields an incidence of 3,108 adults. However, this incidence rate must be adjusted to: reflect cumulative

survival rates in order to calculate prevalence, to determine the percentage of persons who would require services from a Department of Developmental Disabilities, and by the percentage of persons who would actually come forward for service.

To account for these considerations, it is assumed that the proportion of adults who are brain injured who came forward for service in Maryland who had an age of onset before age 22 is the same proportion of adults with brain injury who would come forward given an extension of eligibility to include age on onset after age 22. This assumption is applied to Connecticut incidence rates by the following formula:

> X=N x (incidence rate for adults in CT x # of years in age group/incidence rate for children in CT x years in the age group)
>
> where X=total number of TBI adults with age of onset after age 22 who come forward for service.
>
> and N= the number of adults in Maryland who came forward for service with age of onset before age 22.

Calculating this formula using the age-specific incidence rates drawn from the Connecticut Traumatic Brain Injury Association (1985) thee result is a total of 234 adults with TBI with an age of onset between ages 20 and 60 are likely to come forward for services. To this number, 61% is applied using the Maryland data suggesting that these persons are appropriate for service offered by the Department of Developmental Disabilities. This results in 143 people added to the basic figure for the Department of Developmental Disabilities resulting in a total 794 persons expected to come forward for service given the change in service eligibility suggested here.

b. Independent Living Centers

As noted above, HSRI recommends that the independent living center program in the state be expanded from two centers to eight centers to provide services to all individuals with disabilities. It is also recommended that the centers take on additional responsibility of providing support and follow-along to individuals with moderate and mild disabilities (e.g., individuals with learning disabilities, etc). Using the principles described for the Department of Developmental Disabilities, 331 persons are estimated to come forward for support and follow along. This is based on the Maryland estimates of those requiring support services only (39% of all those who demand services).

However, like the estimates above, this figure must be adjusted to

account for persons suffering traumatic brain injury as an adult. The same procedures outlined above are applied here. As outlined above a total of 234 adults with TBI onset before age 20 are expected to come forward for service. Thirty-one percent of these persons are expected to require follow-along to support services from the independent living centers. This results in 91 persons added to the base figure of 331 resulting in a grand total of 422 persons.

c. Department of Human Resources (Attendant Services)

The Department of Human Resources is currently providing attendant services to a small number of persons with disabilities in the state. There are clearly additional people in the state the could benefit from attendant services to determine potential demand. Allard and Spence (1986) reviewed studies of state attendant care services. In their review, data from the Massachusetts attendant care program was discussed. This program is suggested to have identified and served all persons in Massachusetts who are physically disabled but are capable of employment. Based on this data, .01% of the state population requires personal attendant services. Applying this figure to the adult population in Connecticut, 205 persons are estimated to require personal care services.

d. Department of Health Services

1) Model 50 Waiver

Another recommendation is the movement of the Medicaid Model 50 Waiver to the Department of Health Services. The question, then, is how many children with severe medical problems are potentially eligible for the waiver. According to National Health Interview Survey data, 3.7% of children under age 18 are either unable to engage in major activities (i.e. school) or are limited in the amount or kind of usual activities. Using this figure there are about 28,000 children in Connecticut with this condition. However, this population represents a wide range of developmental and other disabilities not necessarily appropriate for children's health services.

The U.S. Office of Technology Assistance (1987), estimates that there are about 10,000 such children in the United States. Extrapolating to Connecticut census data, there are 113 severely medically involved children in Connecticut. Advocacy representatives urge that these figures should be viewed with caution, however, since there is no reliable data on this target group. The estimate, therefore, may be a substantial underestimate.

2) Family Subsidy

The family cash assistance program in Michigan presently serves 2,754 children. The eligibility criteria for the program are as follows:

1. The child is under age 18

2. The child is recommended by a public school district multi-disciplinary team as Severely Mentally Impaired (SMI), Severely Multiply Impaired (SXI), or Autistic Impaired (AI) and if AI is placed in an SMI, SXI, or AI Type A or Type B classrooms.

3. The child is living in the home of the family who resides in Michigan.

4. The family is headed by a natural parent(s), adoptive parent(s), or legal guardian(s).

5. The family's taxable income does not exceed $60,000 annually.

6. And the family is not receiving a medical subsidy if the child is adopted.

Since Connecticut has differing categories for special education students, a direct translation of these criteria was not possible. Therefore, the 2,754 children under age 18 in Michigan was extrapolated to the corresponding percentage of children in Connecticut resulting in 832 children, whose families would receive cash assistance. Although this a rough estimate it does present a picture of the demand that can be anticipated. It should be kept in mind that this does not include children with physical disabilities alone, or with mental illness.

3. Costs

This section discusses the potential increased costs of services, by service agency, based on the projected number of persons likely to come forward for services as discussed in the previous section.

a. Department of Developmental Disabilities

As discussed, a total of 794 persons are anticipated to come forward for service, given the new service configuration proposed here. According to the survey results of Morrison, Sachs & Smull (1986), 24.8% or 197 of the persons who come forward for service are going to need residential services. Based on the 1986-87 budget of the Department of Mental Retardation, the general fund of $60,741,077 for community residential services serves 2142 clients, giving a general cost of $28,357 per client per year. Based on 197 clients, that will increase the residential service costs by $5,586,329.

According to the Maryland data, 20.2% (161) indicated a need for vocational services, 14.1% (28) indicated a need for social skills training, and 15.4% (30) indicated a need for independent skills training. Although some of these may be duplicate counts, we assume that all of these persons (total= 219) are appropriate for supported work training. We have used the supported work program budget figure for 1986/1987 to base cost estimates since it is likely to be the most appropriate service modality for these individuals. The 1986-87 estimated budget for supported work shows that 1,174 clients were served at a cost of $8,899,571, yielding $7,580 yearly cost per person. Multiplying the per person cost by the total number of persons anticipated, yields a $1,660,020 estimated annual cost increase.

It is anticipated that all newly served persons in the Department of Developmental Disabilities will require case management. Given a 1:40 case manager to consumer ratio, 794 persons will require 20 new case managers. At an approximate annual salary of $20,000, that results in $400,000 in increased costs.

The total costs of these three expanded services results in a grand total of $7,646,349 additional monies needed for an expanded Department of Developmental Disabilities.

b. Independent Living Centers

This report recommends an expansion of the current number of Independent Living Centers to eight in order to meet the needs of the currently eligible Connecticut population. Given an average estimated operating cost of $300,000 per center (based on current expenditures), this proposal will require an additional cost of $1,800,000 for the six new centers. It should be noted that a substantial portion of this money could potentially come from federal resources.

However, this report lso recommends that the existing centers take on additional responsibilities for follow along, counseling and referral

for 422 persons. Using a case manager/consumer ratio of 1:40, that yields an additional need for 10.5 fte case managers. At an average yearly salary of $20,000, a $210,000 additional budget allocation would be necessary to meet these needs.

c. Department of Human Resources

At present the Personal Care Assistance program in DHR is serving 47 people at an annual cost of $315,000, yielding a $6,702 cost per person. The total need for personal care service in Connecticut was estimated at 422 people. We assume that 47 persons of this estimate are presently being served yielding an unmet need of 375 persons. Applying the per person cost to this figure results in an additional need for $2,513,250.

d. Department of Health Services

Given the very wide range of needs presented by children having chronic illness, and the difficulty in estimating the actual number of such children in Connecticut, no estimates are presented on the additional costs for the Model 50 Waiver program.

This project is also recommending the adoption of a cash subsidy program for families with children with disabilities similar to the program presently implemented in Michigan. The Michigan program allots $2,706 per family per year in monthly disbursements. Eight hundred and thirty-two (832) children are estimated to be eligible for this program in Connecticut if similar eligibility requirements are adopted. This would result in an expanded program budget of $2,251,791 to meet these needs.

D. Eligibility Determination

Restructuring Connecticut's services system along the lines recommended in this report will necessitate new procedures for determining eligibility for services. Two of the report's recommendations are worth restating in this context since they will have the greatest impact on eligibility determination. The two recommendations deal with the proposed Department of Developmental Disabilities and the adoption of a functional definition.

In a previous section of this report, we recommended that the mission of the Department of Mental Retardation be expanded. More specifically, it was recommended that the eligible population be expanded to include: a)persons with severe disabilities who b)have a need for ongoing supervision and support; and c) can benefit from the array of services available in the Department of Developmental

Disabilities (e.g. supported work, supervised residential, specialized therapies, intensive case management, etc.).

HSRI recommended further that the state adopt a functional, as opposed to a categorical, definition of disability for determining eligibility for services offered through this new Department of Developmental Disabilities. The most familiar model of a functional definition is the federal definition which has been described in Section III of this report. To reiterate the major elements of this definition, as specified in P.L. 95-602, specify that a developmental disability:

- Is attributable to a mental or physical impairment or combination of mental or physical impairments;
- Is manifested before the person attains age 22;
- Is likely to continue indefinitely;
- Results in substantial limitations in three or more of the following areas of life activity:
  - * Self care
  - * Receptive and expressive language
  - * Learning
  - * Mobility
  - * Self direction
  - * Capacity for Independent Living
  - * Economic self sufficiency
- Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

The implementation of these recommendations will require that the state develop policies that make explicit statements concerning who is eligible for services in this expanded Department of Developmental Disabilities and who fails to meet the requirements of the state's functional definition. These policies will have to be operationalized in one or more screening instruments that can be used by providers to assess eligibility.

As we have noted throughout this report, the federal definition of developmental disabilities has proven to be a useful tool for conceptualizing service system design and planning issues. It has distinct limitations, however, in the area of individual level assessment. It was never intended to be used as a screening device to determine an individual client's eligibility for services.

States that have made the conversion to the federal definition of developmental disabilities or to a modified version of this definition have been forced to confront this politically sensitive and methodologically complicated issue. One of the most difficult aspects of this eligibility determination process is defining what constitutes "substantial functional limitations" in each of the major life activity areas specified above in the federal definition. At this time, there is no consensus concerning the best way to do this. States have approached this measurement task from several different perspectives. However, there is growing consensus that a specific screening instrument is necessary to make the functional approach work and that this instrument should have at least the following attributes:

- The instrument must give providers a reasonably objective way of making decisions about eligibility at the individual client level;

- The instrument must have acceptable levels of reliability, that is, the instrument should yield consistent results across repeated trials;

- The instrument must have face validity as well as concurrent validity, that is local level providers who are using the instrument must believe that it does in fact measure domains that are relevant (face validity) and the results from this instrument should correlate with results from other instruments of known validity;

- The screening instrument should be sensitive to age-related differences among individuals and criteria should reflect different standards for adults and children;

- The instrument should be practical to use. It should be sufficiently comprehensive to cover all relevant dimensions. However, it should be brief enough so that its use does not overburden agency staff who will be administering it.

- Testing of the instrument should include a thorough examination of the implications of setting cutoff points at different levels. These cutoff points will determine the level of disability at which clients will become eligible for services. This level, then, has distinct implications both for the number of clients eligible and the amount of resources that will be required by the Department.

Several states have begun to confront the difficult task of developing screening procedures that are consistent with a functional definition of developmental disabilities. Two states that have actually developed intake assessment instruments are Hawaii and New Jersey.

New Jersey

New Jersey reviewed state efforts in developing screening instruments nationally. They concluded that no adequate instrument existed for determining "substantial functional limitation" in the major life activities areas specified in the federal legislation. As a result, an interdisciplinary team of professionals developed their own instrument, the Critical Adaptive Behaviors Inventory (CABI). A copy of the CABI is included in Appendix A.

The CABI was designed as an eligibility screening tool for adults seeking services through New Jersey's Department of Developmental Disabilities. It assesses functioning in six major life activity areas. These areas correspond to the seven life activity areas specified in the federal definition, the last two -- capacity for independent living and economic self sufficiency -- are collapsed in New Jersey's formulation.

The instrument contains a number of ability statements for each life activity area and records data from four sources: Direct observation by the intake worker; available documents such as psychological reports, medical reports, allied health specialty evaluations and school records; self report by the applicant; and verbal reports by members of the applicant's family, personal care assistants or other reliable individuals (1986, p.6).

Hawaii

Like New Jersey, Hawaii developed its own instrument for assessing

eligibility on a statewide basis. The Hawaii Adaptive Behavior Scale (HABS) was developed in 1984 to determine service eligibility for persons 20 years of age or over. The HABS, a version of which is included in Appendix A, is an adaptation of the American Association of Mental Deficiency Adaptive Behavior Scale. This instrument has been tested in Hawaii. The field test included an examination of the instrument's reliability and validity and an analysis of cutoff points that could be used to define eligibility (Statistical Resources Hawaii, 1987, p 8).

E. Implementation

The comprehensive changes proposed in this report obviously cannot be accomplished quickly. They should be phased in over time and should follow a carefully worked out plan that includes statutory, regulatory, and programmatic objectives. The outline below indicates some of the major tasks that must be undertaken and the approximate time involved.

- *Statutory changes*

  * Adoption of general system principles for application by all specialized and generic agencies in the state;

  * Expansion of the mandate of the current Department of Mental Retardation;

  * Amendments to the Parent Subsidy Aid Act to create a family subsidy program;

  * Movement of the Medicaid Model 50 waiver program to the Department of Health Services;

  * Creation of an Office of Policies Affecting Individuals with Developmental Disabilities and a consumer advisory panel;

  * Possible movement of the Division of Rehabilitation Services (and the Independent Living Program) to the new Office for Policies Affecting Persons with Disabilities;

  * Expansion of the Independent Living Center network;

  * Formalization of DHR case management responsibilities for individuals with disabilities who are capable of self-

direction an who require periodic assistance;

* Designation of Independent Living Centers as responsible agency for the provision of enabling services to persons with moderate and mild disabilities;

* Creation of an independent grievance mechanism attached to the Office of Policy.

- ***Regulatory changes***

  * Development of revised eligibility determination instruments;

  * Adoption of service system principles by all specialized and generic agencies;

  * Development of guidelines to govern follow-along and support services provided by Independent Living Centers;

  * Creation of client satisfaction surveys to monitor the implementation of general system principles;

  * Development of mission statement and operational procedures for new Office of Policy;

  * Revision of mission of the Division of Rehabilitation Services;

  * Development of guidelines to govern eligibility for Parent Subsidy program;

  * Development of regulations to govern provision of support services to families under the Model 50 waiver program;

- *Programmatic changes*

  * Development of service guidelines for the provision of services to new target populations;

  * Training of current DMR and DHR case managers regarding the

needs of those who will be demanding services

* Training of generic and specialized agency staff regarding the needs of persons with disabilities, the nature of the values that should govern the system, and the ways in which the service system principles can be applied in each agency;

* Identification of providers with expertise in the meeting the needs of the new target populations;

* Development of orientation training staff and self-advocates at the independent living centers to introduce them to the needs of individuals requiring support and follow-along;

* Development of an evaluation design to monitor the implementation of the proposed changes.

These are only the highlights of what must be a comprehensive implementation process. Time estimates for the major changes proposed are as follows:

- ***Department of Developmental Disabilities*** -- The transition from a Department of Mental Retardation to a Department of Developmental Disabilities should take approximately five years given the nature of the current demands on the Department of Mental Retardation;

- ***Statewide Independent Living Services*** -- It should take approximately three years to fully flesh out a network of eight centers statewide.

- ***Model 50 waiver program*** -- It should take approximately one year to change the auspices of the Model 50 waiver program to the Department of Health.

- ***Office of Policy Affecting Persons with Disabilities*** -- The creation of the new Office should take approximately one year;

- ***Division of Rehabilitation Services*** -- If a decision is made to move DRS to the new Office of Policy, it should take approximately two years before a complete transition is accomplished.

- ***Family subsidy*** -- The creation and implementation of a family subsidy program should take approximately three years.

F. Conclusion

This analysis represents an important step in the development of a more responsive system of services for persons with disabilities in Connecticut. If the recommendations are implemented in a coherent and thoughtful fashion, the following outcomes should be anticipated:

- Elimination of categorical eligibility criteria for services and an emphasis on need rather than labels;

- Establishment of a case management responsibility for all individuals with disabilities in need of or desirous of such services;

- Creation of an independent grievance mechanism to ensure that individuals are not arbitrarily excluded from services nor subject to inappropriate or inadequate services;

- Provision of multiple means for holding generic agencies accountable for the provision of services to people with disabilities;

- Provision of multiple forums for priority-setting and identification of unmet needs;

- Enhancement of interagency collaboration through the new Office of Issues Affecting Individuals with Disabilities;

- Expansion of the independent living program statewide;

- Recognition of the unique needs of families with children with chronic illnesses and disabilities.

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APPENDIX A

Screening Instruments

APPENDIX I
INTAKE/ELIGIBILITY TASK FORCE
CRITICAL ADAPTIVE BEHAVIORS INVENTORY

INTRODUCTION

The legislation that established the Division of Developmental Disabilities (DDD) states that "developmental disability means a severe, chronic disability of a person which: (1) is attributable to a mental or physical impairment or combination of mental or physical impairments; (2) is manifest before age 22; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of major life activity, that is, self-care, receptive and expressive language, learning, mobility, self-direction, and capacity for independent living or economic self-sufficiency; and (5) reflects the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of life-long or extended duration and are individually planned and coordinated..."

Criterion (4) of the above definition of developmental disability provides the primary rationale for the Critical Adaptive Behaviors Inventory (CABI). Criterion (4) mandates that eligibility for DDD services be in part dependent upon the functional assessment of the real life limitations resulting from the applicant's physical and/or mental impairments. It is inferred that inclusion in a disability and/or disease classification is neither necessary nor sufficient to satisfy criterion (4). A valid assessment of the applicant's current functional abilities is required. This is the role of the CABI in the DDD intake process.

DESCRIPTION

The CABI is specifically designed to facilitate the screening of adult applicants to the DDD by assessing the applicant's functioning in the 6 areas of Major Life Activity specified in the DDD legislation. The intent is to assess only behaviors that are critical for independent adaptation to the ordinary demands of adult life.

A variety of Ability Statements are presented within each Major Life Activity. Each statement describes a critical ability and where appropriate the component skills that comprise the ability. In some instances examples are offered to clarify various aspects of the statement. Some Ability Statements assess primarily physical abilities, some assess primarily mental abilities, and others a combination of physical and mental abilities. There is space for short comments following each statement wherein the intake worker may record the specific strengths and weaknesses of the applicant's performance.

Each Ability Statement is presented in the positive, that is, it describes a critical ability, not a deficiency. The intake worker's task is to assess whether the applicant possesses the ability as stated (scored "YES"), or does not possess that ability (scored "NO"). If the intake worker is not able to reach a "YES" or "NO" conclusion, for whatever reason, provision is made for recording a no conclusion response (scored "?").

The CABI provides for the recording of information from four sources for each Ability Statement. The sources are: direct observation by the intake worker (OBSERVATION), available documents such as psychological reports, medical reports, allied health specialty evaluations, and school records (DOCUMENTS), self-report by the applicant (APPLICANT), and verbal reports by members of the applicant's family, personal care assistants, or other reliable individuals (INFORMANT).

In addition to the Ability Statements there is an Applicant Data Sheet that provides for the recording of demographic and other applicant information necessary for the intake process. It also provides for a convenient and traditional (non-threatening) starting point for the administration of the CABI.

ADMINISTRATION

The CABI is intended for administration by a trained intake worker. The Applicant Data Sheet and Ability Statements provide the basis for a structured interview and functional assessment wherein the intake worker systematically gathers information about the applicant. The process will normally proceed as follows:

1. The intake worker provides the applicant (and informant) with an overview of the DDD and the rationale for requiring a functional assessment.

2. The intake worker asks the applicant to reiterate, in the applicant's own words, the rationale for the functional assessment. This is to ensure that the applicant (and informant) understand the process and will therefore cooperate fully, and also to provide an opportunity for the intake worker to observe the applicant's ability to learn new information and concepts. Ability Statement III-6 can be completed at this time.

3. The intake worker interviews the applicant (and informant) using the Applicant Data Sheet to structure the interview, but maintaining enough flexibility to follow-up on opportunities for observation of the applicant's functional skills. For example, Ability Statements II-1, II-2, II-3, and II-7 may be observed and recorded during this part of the interview.

4. The intake worker continues the interview using the Ability Statements for structure. The intake worker has the option of paraphrasing the Statements to suit the situation, reading them directly to the applicant, or asking the applicant to perform relevant activities that may offer the opportunity to observe several abilities simultaneously.

5. After all the Ability Statements have been completed (the DOCUMENTS source of information may be completed later) the intake worker reviews the results with the applicant (and informant).

6. If necessary, documents are collected and the relevant information recorded under the appropriate Ability Statements.

7. The CABI is scored and a Determination of Functional Eligibility made.

While the majority of the assessment will normally be accomplished during a visit to the applicant's place of residence, the intake worker is encouraged to be creative in arranging for opportunities to observe the applicant's behavior directly in a variety of situations. For example, the intake worker can insist on speaking to the applicant personally on the phone, if at all possible, when arranging the home visit. Parts of the receptive and expressive language assessment can be completed at that time. It follows that there is no required order to the assessment of the 6 areas of Major Life Activity, or the specific Ability Statements within an area. Likewise, entries can be made for the four sources of information in any order as the information is developed.

Direct observation by the intake worker is the preferred source of information. Every effort should be made to reach a "YES" or "NO" conclusion for each Ability Statement. It should be noted here that direct observation does not necessarily mean that the intake worker must observe the applicant performing or attempting to perform the entire and exact activity described in the Ability Statement. Some judgment must be applied. For example, in assessing the applicant's ability to bathe independently it is not required that the applicant actually undress and bathe in front of the intake worker. A simulated bath may be employed, wherein the applicant is asked to go through the motions of taking a bath, perhaps even transferring into and out of the tub or shower while clothed. Also, if the applicant is unable to perform a component skill in a chain of skills, then a "NO" verdict may be reached without observing the remaining component skills. For example, if it has already been observed that the applicant cannot put on outerclothes independently, then it is not necessary to assess whether or not underclothes can be put on or taken off independently. The answer is negative to "dresses and undresses self independently..." and a "NO" is recorded for this Ability Statement under OBSERVATION.

Since there is provision for the no conclusion response ("?") an entry should be made under all four sources of information for every Ability Statement. This will help to ensure that items are not skipped accidently and that the maximum amount of information has been developed.

SCORING

Each Major Life Activity is first scored independently. If one (or more) Ability Statement is marked "NO" under OBSERVATION then the applicant has a SUBSTANTIAL FUNCTIONAL LIMITATION in that Major Life Activity. If all the Ability Statements are marked "YES" or "?" under OBSERVATION, and all Statements marked "?" under OBSERVATION are marked "YES" under at least one other Source of Information, then the applicant has NO SUBSTANTIAL FUNCTIONAL LIMITATION in that Major Life Activity. If neither of the above two definitive findings are established, then the applicant has a POSSIBLE FUNCTIONAL LIMITATION in that Major Life Activity.

After all 6 of the Major Life Activities are scored as above, the results are transferred to the Summary Sheet. Each of the Major Life Activities is marked as SUBSTANTIAL FUNCTIONAL LIMITATION, NO SUBSTANTIAL FUNCTIONAL LIMITATION, or POSSIBLE FUNCTIONAL LIMITATION. A total (1-6) is arrived at for each of these columns, and then a DETERMINATION OF FUNCTIONAL ELIGIBILITY is made. If the SUBSTANTIAL FUNCTIONAL LIMITATION column totals 3 or more, then the applicant is ELIGIBLE. If the NO SUBSTANTIAL FUNCTIONAL LIMITATION column totals 4 or more, then the applicant is NOT ELIGIBLE. If neither of the above two definitive findings are established, then there is FURTHER ASSESSMENT REQUIRED.

CRITICAL ADAPTIVE BEHAVIORS INVENTORY

ABILITY STATEMENTS

MAJOR LIFE ACTIVITY: CATEGORY I SELF-CARE	SOURCE OF INFORMATION OBSERVATION: YES / NO / ?	DOCUMENTS: YES / NO / ?	APPLICANT: YES / NO / ?	INFORMANT: YES / NO / ?
1: Applicant feeds self independently including cutting food, lifting food and drink to mouth, chewing, and swallowing when served a prepared meal and using personally owned assistive devices if necessary. Comments:				
2: Applicant toilets self independently including transferring to toilet, wiping self, and transferring from toilet using personally owned assistive devices if necessary. If alternative methods of urinary voiding or fecal evacuation are applicable, applicant independently completes entire routine. Comments:				
3: Applicant independently selects attire appropriate as to season and activity. Comments:				
4: Applicant dresses and undresses self independently including underclothes, outerclothes, socks, and shoes, using personally owned adapted clothes and/or assistive devices if necessary. Comments:				
5: Applicant bathes self independently including transfer to tub or shower, adjusting water, scrubbing, transfer from tub or shower, and drying, using personally owned assistive devices if necessary. Comments:				
6: Applicant self-administers oral medications including opening container, obtaining correct dosage, placing medications in mouth, swallowing (with or without liquids, as appropriate), and closing container, using personally owned assistive devices if necessary. Comments:				
7: Applicant's abilities in the self-care category of major life activities, as measured by the above statements, are functional most of the time. That is, if functional ability fluctuates across time due to the nature of the developmental disability, the applicant is impaired in self-care less than an average of one full day a month for reasons related to the developmental disability. Comments:				

CATEGORY I

_____ SUBSTANTIAL FUNCTIONAL LIMITATION (One or more Statement marked No under Observation.

_____ NO SUBSTANTIAL FUNCTIONAL LIMITATION (All Statements are marked Yes or ? under Observation, and all Statements marked ? under Observation are marked Yes under at least one other Source of Information.)

_____ POSSIBLE FUNCTIONAL LIMITATION (Neither Substantial Functional Limitation or No Substantial Functional Limitation.)

APPLICANT'S NAME: _____ ID#: _____

CRITICAL ADAPTIVE BEHAVIORS INVENTORY

ABILITY STATEMENTS

MAJOR LIFE ACTIVITY: CATEGORY II RECEPTIVE AND EXPRESSIVE LANGUAGE	SOURCE OF INFORMATION											
	OBSERVATION			DOCUMENTS			APPLICANT			INFORMANT		
	YES	NO	?	YES	NO	?	YES	NO	?	YES	NO	?
1: Applicant can hear and comprehend the content of ordinary spoken conversations in the applicant's primary language, using a hearing aid and/or other personally owned assistive devices if necessary. Comments:												
2: Applicant has sufficiently intelligible speech to communicate common words to individuals of casual acquaintance in the community. Comments:												
3: Applicant has sufficient vocabulary, grammatic ability, and/or non-verbal communications skills to conduct ordinary business with individuals of casual acquaintance in the community. Comments:												
4: Applicant can conduct a functional two way conversation over the telephone such as scheduling personal appointments or obtaining consumer information, using an amplified telephone and/or other personally owned assistive devices if necessary. Comments:												
5. Applicant has sufficient sight and reading ability to access and comprehend ordinary written text such as in popular magazines and newspapers, using eyeglasses, dictionary, and/or other personally owned assistive devices if necessary. Comments:												
6: Applicant has sufficient physical skills, vocabulary, and grammatic ability to write or type a functional letter such as a personal note to a friend or a response to a business or government communication, using eyeglasses, typewriter, wordprocessor, and/or other personally owned assistive devices if necessary. Comments:												
7: Applicant's abilities in the receptive and expressive language category of major life activities, as measured by the above statements, are functional most of the time. That is, if functional ability fluctuates across time due to the nature of the developmental disability, the applicant is impaired in receptive and expressive language less than an average of one full day a month for reasons related to the developmental disability. Comments:												

CATEGORY II

_____ SUBSTANTIAL FUNCTIONAL LIMITATION (One or more Statement marked No under Observation.

_____ NO SUBSTANTIAL FUNCTIONAL LIMITATION (All Statements are marked Yes or ? under Observation, and all Statements marked ? under Observation are marked Yes under at least one other Source of Information.)

_____ POSSIBLE FUNCTIONAL LIMITATION (Neither Substantial Functional Limitation or No Substantial Functional Limitation.)

APPLICANT'S NAME: _____ ID#: _____

CRITICAL ADAPTIVE BEHAVIORS INVENTORY

ABILITY STATEMENTS

MAJOR LIFE ACTIVITY: CATEGORY III LEARNING	SOURCE OF INFORMATION OBSERVATION			DOCUMENTS			APPLICANT			INFORMANT		
	YES	NO	?	YES	NO	?	YES	NO	?	YES	NO	?
1: Applicant has sufficient hearing and/or sight, and mental ability to access and comprehend the content of ordinary television and/or radio programming using a hearing aid, eyeglasses, and/or other personally owned assistive devices if necessary. Comments:												
2: Applicant has sufficient sight, sense of touch, and/or sense of smell to identify common domestic products and is able to explain their common uses. Comments:												
3: Applicant has sufficient money skills, and sight and/or sense of touch to identify pennies, nickels, dimes, and quarters, and to calculate the value of any combination of these coins up to $2.00. Comments:												
4: Applicant has sufficient time skills, and sight, hearing, and/or sense of touch to tell the time of day to the quarter hour including A.M. and P.M., given a clock or watch appropriate for the applicant and using eyeglasses, hearing aid, and/or other personally owned assistive devices if necessary. Comments:												
5. Applicant is able to provide a reasonably complete and accurate personal history including, for example, name, date of birth, place of birth, place of residence (including street address, city, and state), telephone number, Social Security number, nature and cause of disabling condition, education and/or employment data, etc. Comments:												
6: Applicant is able to state in general terms the reason for this functional assessment after being given a full explanation by the intake worker. Comments:												
7: Applicant's abilities in the learning category of major life activities, as measured by the above statements, are functional most of the time. That is, if functional ability fluctuates across time due to the nature of the developmental disability, the applicant is impaired in learning less than an average of one full day a month for reasons related to the developmental disability. Comments:												

CATEGORY III

_____ SUBSTANTIAL FUNCTIONAL LIMITATION (One or more Statement marked No under Observation.

_____ NO SUBSTANTIAL FUNCTIONAL LIMITATION (All Statements are marked Yes or ? under Observation, and all Statements marked ? under Observation are marked Yes under at least one other Source of Information.)

_____ POSSIBLE FUNCTIONAL LIMITATION (Neither Substantial Functional Limitation or No Substantial Functional Limitation.)

APPLICANT'S NAME: _____ ID#: _____

CRITICAL ADAPTIVE BEHAVIORS INVENTORY

ABILITY STATEMENTS

MAJOR LIFE ACTIVITY: CATEGORY IV MOBILITY	SOURCE OF INFORMATION OBSERVATION YES	NO	?	DOCUMENTS YES	NO	?	APPLICANT YES	NO	?	INFORMANT YES	NO	?
1: Applicant moves about independently and safely within both indoor and outdoor environments using a wheelchair, crutches, braces, cane, and/or other personally owned assistive devices if necessary. Comments:												
2: Applicant gets up and down low curbs up to six inches high independently and safely using wheelchair, crutches, braces, cane, and/or other personally owned assistive devices if necessary. Comments:												
3: Applicant is able to pick up a towel from the floor using personally owned assistive devices if necessary. Comments:												
4: Applicant gets in and out of bed independently and safely using personally owned assistive devices if necessary. Comments:												
5: Applicant independently and safely operates ordinary household equipment such as TV, radio, oven/range, vacuum cleaner, etc. using personally owned assistive devices if necessary. Comments:												
6: Applicant crosses streets with light traffic and/or streets with traffic lights independently and safely. Comments:												
7: Applicant gets in and out of his/her place of residence independently and safely, including locking and unlocking doors. Comments:												
8: Applicant's abilities in the mobility category of major life activities, as measured by the above statements, are functional most of the time. That is, if functional ability fluctuates across time due to the nature of the developmental disability, the applicant is impaired in mobility less than an average of one full day a month for reasons related to the developmental disability. Comments:												

CATEGORY IV

_____ SUBSTANTIAL FUNCTIONAL LIMITATION (One or more Statement marked No under Observation.

_____ NO SUBSTANTIAL FUNCTIONAL LIMITATION (All Statements are marked Yes or ? under Observation, and all Statements marked ? under Observation are marked Yes under at least one other Source of Information.)

_____ POSSIBLE FUNCTIONAL LIMITATION (Neither Substantial Functional Limitation or No Substantial Functional Limitation.)

APPLICANT'S NAME: _____ ID#: _____

CRITICAL ADAPTIVE BEHAVIORS INVENTORY

ABILITY STATEMENTS

MAJOR LIFE ACTIVITY: CATEGORY V SELF-DIRECTION	SOURCE OF INFORMATION											
	OBSERVATION			DOCUMENTS			APPLICANT			INFORMANT		
	YES	NO	?	YES	NO	?	YES	NO	?	YES	NO	?
1: Applicant makes essentially independent daily personal decisions regarding a schedule of activities including when to get up, what to do (e.g. work, leisure, home chores, etc.), and when to go to bed. Comments:												
2: Applicant makes essentially independent major life decisions such as choice of type and location of living arrangements, marriage, and career choice. Comments:												
3: Applicant possesses adequate social skills to establish interpersonal relationships with friends and/or relatives. Comments:												
4. Applicant makes essentially independent daily personal decisions regarding diet including when to eat, where to ear, and what to eat. Comments:												
5. Applicant is essentially independent in managing personal finances including making decisions regarding allocation of financial resources and keeping track of financial obligations. Comments:												
6: Applicant is capable of self-referral for routine medical and dental checkups and treatment including selecting the doctor, arranging for an appointment, and providing a medical history as necessary. Comments:												
7: Applicant demonstrates sufficient assertiveness skills to express personal opinions, request assistance when needed, and protect self from exploitation by others. Comments:												
8. Applicant's abilities in the self-direction category of major life activities, as measured by the above statements, are functional most of the time. That is, if functional ability fluctuates across time due to the nature of the developmental disability, the applicant is impaired less than an average of one full day a month for reasons related to the developmental disability. Comments:												

CATEGORY V

_____ SUBSTANTIAL FUNCTIONAL LIMITATION (One or more Statement marked No under Observation.

_____ NO SUBSTANTIAL FUNCTIONAL LIMITATION (All Statements are marked Yes or ? under Observation, and all Statements marked ? under Observation are marked Yes under at least one other Source of Information.)

_____ POSSIBLE FUNCTIONAL LIMITATION (Neither Substantial Functional Limitation or No Substantial Functional Limitation.)

APPLICANT'S NAME: _____ ID#: _____

CRITICAL ADAPTIVE BEHAVIORS INVENTORY

ABILITY STATEMENTS

MAJOR LIFE ACTIVITY: CATEGORY VI CAPACITY FOR INDEPENDENT LIVING OR ECONOMIC SELF-SUFFICIENCY	SOURCE OF INFORMATION											
	OBSERVATION			DOCUMENTS			APPLICANT			INFORMANT		
	YES	NO	?	YES	NO	?	YES	NO	?	YES	NO	?
1. Applicant independently prepares light meals on occasion. Comments:												
2: Applicant is aware of a variety of community activities such as religious services, continuing education, sports, volunteer organizations, movies, shopping, visiting friends, etc. and independently selects and participates in at least one on a regular basis. Comments:												
3: Applicant can be left alone for periods of time up to 24 hours without being considered to be at risk. Comments:												
4: Applicant is able to state in general terms several requirements of being a good worker, such as being prompt, attending regularly, accepting supervision, getting along with coworkers, etc. Comments:												
5: Applicant is able to state several approaches to finding a job, such as going to an employment agency, responding to ads, using personal contacts, etc. Comments:												
6: Applicant is able to state a vocational preference and describe with reasonable accuracy the education and skills required. Comments:												
7: Applicant demonstrates insight regarding the obstacles to independent living and/or employment consequent to the applicant's disability. Comments:												
8. Applicant's abilities in the capacity for independent living or economic self-sufficiency category of major life activities, as measured by the above statements, are functional most of the time. That is, if functional ability fluctuates across time due to the nature of the developmental disability, the applicant is impaired in capacity for independent living or economic self-sufficiency less than an average of one full day a month for reasons related to the developmental disability. Comments:												

CATEGORY VI

_____ SUBSTANTIAL FUNCTIONAL LIMITATION (One or more Statement marked No under Observation.

_____ NO SUBSTANTIAL FUNCTIONAL LIMITATION (All Statements are marked Yes or ? under Observation, and all Statements marked ? under Observation are marked Yes under at least one other Source of Information.)

_____ POSSIBLE FUNCTIONAL LIMITATION (Neither Substantial Functional Limitation or No Substantial Functional Limitation.)

APPLICANT'S NAME: _____ ID#: _____

CRITICAL ADAPTIVE BEHAVIORS INVENTORY

SUMMARY SHEET

MAJOR LIFE ACTIVITY	SUBSTANTIAL FUNCTIONAL LIMITATION	NO SUBSTANTIAL FUNCTIONAL LIMITATION	POSSIBLE FUNCTIONAL LIMITATION
CATAGORY I: SELF-CARE			
CATAGORY II: RECEPTIVE AND EXPRESSIVE LANGUAGE			
CATAGORY III: LEARNING			
CATAGORY IV: MOBILITY			
CATAGORY V: SELF-DIRECTION			
CATAGORY VI: CAPACITY FOR INDEPENDENT LIVING OR ECONOMIC SELF-SUFFICIENCY			
		TOTALS	

SUMMARY COMMENTS: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____ _____ _____

Intake Worker's Name | Intake Worker's Signature | Date Assessment Completed

DETERMINATION OF FUNCTIONAL ELIGIBILITY

_____ ELIGIBLE (Substantial Functional Limitation in 3 or more Major Life Activity catagories.)

_____ NOT ELIGIBLE (No Substantial Functional Limitation in 4 or more Major Life Activity catagories.)

_____ FURTHER ASSESSMENT REQUIRED (Neither Eligible or Not Eligible.)

APPLICANT'S NAME: _____ ID#: _____

HABS (HAWAII ADAPTIVE BEHAVIOR SCALE)

SELF-CARE

1. Use of Table Utensils (Circle only ONE)

Uses knife and fork correctly and neatly	6
Uses table knife for cutting or spreading	5
Feeds self with spoon and fork - neatly	4
Feeds self with spoon and fork - considerable spilling	3
Feeds self with spoon - neatly	2
Feeds self with spoon - considerable spilling	1
Feeds self with fingers or must be fed	0

2. Drinking (Circle only ONE)

Drinks without spilling, holding glass in one hand	3
Drinks from cup or glass unassisted-neatly	2
Drinks from cup or glass unassisted - considerable spilling	1
Does not drink from cup or glass unassisted	0

3. Table Manners (Check ALL statements which apply)

Swallows food without chewing	___
Chews food with mouth open	___
Drops food on table or floor	___
Uses napkin incorrectly or not at all.	___
Talks with mouth full	___
Takes food off others' plates	___
Eats too fast or too slow	___
Plays in food with fingers	___
Does not apply, e.g., because he or she is bedfast, and/or has liquid food only. (If checked, enter "0" in the square to the right.)	___
8 minus number checked - score for this item.	___

4. Toilet Training (Circle only ONE)

Never had toilet accidents	4
Never had toilet accidents during the day	3
Occasionally has toilet accidents during the day	2
Frequently has toilet accidents during the day	1
Not toilet trained at all	0

5. Self-Care at Toilet (Check ALL statements which apply)

Lowers pants at the toilet without help	___
Sits on toilet seat without help	___
Uses toilet tissue appropriately	___
Flushes toilet after use	___
Puts on clothes without help	___
Washes hands without help	___
Add total checked	___

6. Washing Hands and Face (Check ALL statements which appl

Washes hands with soap	___
Washes face with soap	___
Washes hands and face with water	___
Dries hands and face	___
Add total checked	___

7. Bathing (circle only ONE)

Prepares and completes bathing unaided	6
Washes and dries self completely without prompting or helping	5
Washes and dries self reasonably well with prompting	4
Washes and dries self with help	3
Attempts to soap and wash self	2
Cooperates when being washed and dried by others	1
Makes no attempt to wash or dry self	0

8. Personal Hygiene (Check ALL statements which apply)

Has strong underarm odor	___
Does not change underwear regularly by self	___
Skin is often dirty if not assisted	___
Does not keep nails by self	___
Does not apply, e.g., because he or she is completely dependent on others. (If checked, enter "0" in the square to the right.)	___
4 minus number checked - score for this item.	___

9. Tooth Brushing (Circle only ONE)

Applies toothpaste and brushes teeth with up and down motion	5
Applies toothpaste and brushes teeth	4
Brushes teeth without help, but cannot apply toothpaste	3
Brushes teeth with supervision	2
Cooperates in having teeth brushed	1
Makes no attempt to brush teeth	0

10. Menstruation (circle only ONE) (For males, circle "no menstruation")

No menstruation	5
Cares for self completely for menstruation without assistance or reminder	5
Cares for self reasonably well during menstruation	4
Helps in changing pads during menstruation	3
Indicates pad needs changing during menstruation	2
Indicates that menstruation had begun	1
Will not care for self or seek help during menstruation	0

11. Dressing (Circle only ONE)

Completely dresses self	5
Completely dresses self with verbal prompting only	4
Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help	3
Dresses self with help in pulling or putting on most clothes and fastening them	2
Cooperates when dressed by extending arms or legs	1
Must be dressed completely	0

12. Undressing at Appropriate Times (Circle only ONE)

Completely undresses self	5
Completely undresses self with verbal prompting only	4
Undresses self by unfastening (unzipping, unbuttoning, unsnapping) clothes with help and pulling or taking them off with verbal prompting	3
Undresses self with help in unfastening and pulling or taking off most clothes	2
Cooperates when undressed by extending arms or legs	1
Must be completely undressed	0

13. Shoes (Check ALL statements which apply)

Puts on shoes correctly without assistance	___
Removes shoes without assistance	___
Add total checked	/___/

Total Self-Care Score ≤44 = Substantial deficit ___

LANGUAGE

1. Complex Instructions (Check ALL statements which apply)

Understands instructions containing prepositions, e.g., "on", "in", "behind", "under", etc.	___
Understands instructions referring to the order in which things must be done, e.g., "first do-then do"	___
Understands instructions requiring a decision "If-, do this, but if not, do-"	___
Add total checked	/___/

2. Preverbal Expression (Check ALL statements which apply)

Nods head or smiles to express happiness	___
Indicates hunger	___
Indicates wants by pointing or vocal noises	___
Chuckles or laughs when happy	___
Expresses pleasure or anger by vocal noises	___
Is able to say at least a few words (Enter "6" if checked, regardless of other items.)	___
Add total checked	/___/

3. Articulation (Check ALL statements which apply--if no speech, check "None" and enter "0" in the square)

Speech is low, weak, whispered or difficult to hear	___
Speech is slowed, deliberate, or labored	___
Speech is hurried, accelerated, or pushed	___
Speaks with blocking, halting, or other irregular interruptions	___
None of the above	___
Add total checked	/___/

4. Sentences (Circle only ONE)

Sometimes uses complex sentences containing "because", "but", etc.	3
Asks questions using words such as "why", "how", "what", etc.	2
Speaks in simple sentences	1
Speaks in primitive phrases only, or is non-verbal	0

5. Word Usage (Circle only ONE)

Talks about action when describing pictures	4
Names people or objects when describing pictures	3
Names familiar objects	2
Asks for thing by their appropriate names	1
Is non-verbal or nearly non-verbal	0

Total Speech Score ≤13 = substantial deficit ___

LEARNING

1. Numbers (Circle only ONE)

Does simple addition and subtraction	5
Counts ten or more objects	4
Mechanically counts to ten	3
Counts two objects by saying "one...two"	2
Counts two objects by saying "one...two" or "a lot"	1
Has no understanding of numbers	0

2. Reading (Circle only ONE)

Reads books suitable for children nine years or older	5
Reads books suitable for children seven years or older	4
Reads simple stories or comics	3
Reads various signs, e.g., "NO PARKING", "ONE WAY", "MEN", "WOMEN", etc.	2
Recognizes ten or more words by sight	1
Recognizes fewer than ten words or none at all	0

3. Writing (Circle only ONE)

Writes sensible and understandable letters	5
Writes short notes and memos	4
Writes or prints forty words	3
Writes or prints ten words	2
Writes or prints own name	1
Cannot write or print any words	0

4. Time (Check ALL statements which apply)

Tells time by clock or watch correctly to the minute ___
Understands time intervals, e.g., between "3:30" and "4:30" as "quarter past nine" ___
Associates time on clock with various actions and events ___
None of the above ___

Add total checked ___

5. Time Concept (Check ALL statements which apply)

Names the days of the week
Refers correctly to "morning" and "afternoon" ___
Understands difference between day-week, minute-hour, month-year, etc. ___
None of the above ___

Total Learning Score ≤12 = substantial deficit ___

MOBILITY

1. Body Balance (Circle only ONE)

Stands on "tiptoe" for ten seconds if asked 5
Stands on one foot for two seconds if asked 4
Stands without support 3
Stands with support 2
Sits without support 1
Can do none of the above 0

2. Walking and Running (Check ALL statements which apply)

Walks alone
Walks up and down stairs alone ___
Walks down stairs by alternating feet ___
Runs without falling often ___
Hops, skips or jumps ___

Add total checked ___

3. Control of Hands (Check ALL statements which apply)

Catches a ball
Throws a ball overhand ___
Lifts cup or glass ___
Grasps with thumb and finger ___

Add total checked ___

Total Mobility Score ≤6 ___

SELF DIRECTION

1. Initiative (Circle only ONE)

Initiates most of own activities, e.g., tasks, games, etc. 3
Asks if there is something to do, or explores surroundings, e.g., home, yard, etc. 2
Will engage in activities only if assigned or directed 1
Will not engage in assigned activities, e.g., putting away toys, etc. 0

2. Passivity (Check ALL statements which apply)

Has to be made to do things
Has no ambition ___
Seems to have no interest in things ___
Finishes tasks last because of wasted time ___
Is unnecessarily dependent on others for help ___
Movement is slow and sluggish ___

Does not apply, e.g., because he or she is totally dependent on others. (If checked, enter "0" in the square to the right.)
6 minus number checked - score for this item. ___

3. General Responsibility (Circle only ONE)

Very conscientious and assumes much responsibility—makes a special effort, the assigned activities are always performed 3
Usually dependable—makes an effort to carry out responsibility; one can be reasonably certain that the assigned activity will be performed 2
Unreliable—makes little effort to carry out responsibility one is uncertain that the assigned activity will be performed 1
Not given responsibility, is unable to carry out responsibility at all 0

4. Attention (Circle only ONE)

Will pay attention to purposeful activities for more than fifteen minutes, e.g., playing games, reading cleaning up 4
Will pay attention to purposeful activities for at least fifteen minutes 3
Will pay attention to purposeful activities for at least ten minutes 2
Will pay attention to purposeful activities for at least five minutes 1
Will not pay attention to purposeful activities for as long as five minutes 0

5. Persistence (Check ALL statements which apply)

Becomes easily discouraged
Fails to carry out tasks ___
Jumps from one activity to another ___
Needs constant encouragement to complete task ___
None of the above ___

Does not apply, e.g., because he or she is totally incapable of any organized activities. (If checked, enter "0" in the square to the right.)
4 minus number checked - score for this item. ___

6. Leisure Time Activity (Check ALL statements which apply

Organizes leisure time on a fairly complex level, e.g., plays billiards, fishes, etc. ___
Has hobby, e.g., painting, embroidery, collecting stamps or coins ___
Organizes leisure time adequately on a simple level, e.g., watching television, listening to phonograph, radio, etc. ___

Add total checked ___

7. Personal Belongings (Circle only ONE)

Very dependable—always takes care of personal belongings 3
Usually dependable—usually takes care of personal belongings 2
Unreliable—seldom takes care of personal belongings 1
Not responsible at all—does not take care of personal belongings 0

8. Cooperation (Circle only ONE)

Offers assistance to others 2
Is willing to help if asked 1
Never helps others 0

9. Consideration for Others (Check ALL statements which apply)

Shows interest in the affairs of others —
Takes care of others' belongings —
Directs or manages the affairs of others when needed —
Shows consideration for others' feelings —

Add total checked ☐

10. Awareness of Others (Check ALL statements which apply)

Recognizes own family
Recognizes people other than family —
Has information about others, e.g., job, address, relation to self —
Knows the names of people close to him, e.g., classmates, neighbors —
Knows the names of people not regularly encountered —

Add total checked ☐

11. Interaction with Others (Circle only ONE)

Interacts with others in group games or activity 3
Interacts with others for at least a short period of time, e.g., showing or offering toys, clothing or objects 2
Interacts with others imitatively with little interaction 1
Does not respond to others in a socially acceptable manner 0

12. Participation in Group Activities (Circle only ONE)

Initiates group activities (leader and organizer) 3
Participates in group activities spontaneously and eagerly (active participant) 2
Participates in group activities if encouraged to do so (passive participant) 1
Does not participate in group activities 0

13. Selfishness (Check ALL statements which apply)

Refuses to take turns
Does not share with others —
Gets mad if he does not get his way —
Interrupts aide or teacher who is helping another person —

Does not apply, e.g., because he or she has no social interaction or is profoundly withdrawn. (If checked, enter "0" in the square to the right.)
4 minus number checked = score for this item. ☐

14. Social Maturity (Check ALL statements which apply)

Is too familiar with strangers
Is afraid of strangers —
Does anything to make friends —
Likes to hold hands with everyone —
Is at someone's elbow constantly —

Does not apply, e.g., because he or she has no socia interaction or is profoundly withdrawn. (If chec enter "0" in the square to the right.)
5 minus number checked = score for this item. —

Total Self Direction Score
≤30 = substantial deficit —

INDEPENDENT LIVING

1. Sense of Direction (Circle only ONE)

Goes a few blocks from hospital or school ground or several blocks from home without getting lost
Goes around hospital ground or a few blocks from home without getting lost
Goes around cottage, ward, or home alone
Gets lost whenever leaving own living area

2. Public Transportation (Check ALL statements which ap

Drives car
Rides on long distance bus or plane independently —
Rides in taxi independently —
Rides city bus for unfamiliar journeys independently —
Rides city bus for familiar journeys independently —

Add total checked ☐

3. Money Handling (Circle only ONE)

Uses bank facilities independently
Makes change correctly but does not use bank facilities
Adds coins of various denominations, up to one dollar
Uses money, but does not make change correctly
Does not use money

4. Budgeting (Check ALL statements which apply)

Saves money or tokens for a particular purpose —
Spends money with some planning —
Controls own major expenditures —

Add total checked ☐

5. Errands (Circle only ONE)

Goes to several shops and specifies different items
Goes to one shop and specifies one item
Goes on errands for simple purchasing without a note
Goes on errands for simple purchasing with a note
Cannot be sent on errands

6. Purchasing (Circle only ONE)

Buys all own clothing 5
Buys own clothing accessories 4
Makes minor purchases without help (candy, soft drinks, etc.) 3
Does shopping with slight supervision 2
Does shopping with close supervision 1
Does no shopping 0

7. Room Cleaning (Circle only ONE)

Cleans room well, e.g., sweeping, dusting and tidying 2
Cleans room but not thoroughly 1
Does not clean room at all 0

8. Laundry (Check ALL statements which apply)

Washes clothing
Dries clothing
Folds clothing
Irons clothing when appropriate

Add total checked

9. Table Setting (Circle only ONE)

Places all eating utensils, as well as napkins, salt, pepper, sugar, etc. in positions learned 3
Places plates, glasses, and utensils in positions learned 2
Places silver, plates, cups, etc. on the table 1
Does not set table at all 0

10. Meal Preparation

Prepares an adequate complete meal (may use canned or frozen food) 3
Mixes and cooks simple food, e.g., fried eggs, makes pancakes, cooks TV dinners, etc. 2
Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc. 1
Does not prepare food at all 0

11. Table Clearing (Circle only ONE)

Clears table of breakable dishes and glassware 2
Clears table of unbreakable dishes and silverware 1
Does not clear table at all 0

12. General Domestic Activity (Check ALL statements which apply)

Washes dishes
Makes bed neatly
Helps with household chores when asked
Does household tasks routinely

Add total checked

13. Telephone (Check ALL statements which apply)

Uses telephone directory
Uses pay telephone
Makes telephone calls from private telephone
Answers telephone appropriately
Takes telephone messages

Add total checked

14. Miscellaneous Independent Functioning (Check ALL statements which apply)

Prepares own bed at night
Goes to bed unassisted, e.g., getting in bed, covering with blanket, etc.
Has ordinary control of appetite, eats moderately
Knows postage rates, buys stamps from Post Office
Looks after personal health, e.g., changes wet clothes
Deals with simple injuries, e.g., cuts, burns
Knows how and where to obtain a doctor's or dentist's help
Knows about welfare facilities in the community

Add total checked

Total Independent Living Score
≤ 28 = substantial deficit

ECONOMIC SELF SUFFICIENCY

1. Job Complexity (Circle only ONE)

Performs a job requiring use of tools or machinery, e.g., shop work, sewing, etc. 2
Performs simple work, e.g., simple gardening, mopping floor, emptying trash, etc. 1
Performs no work at all 0
(If circled, go on to Item 4)

2. Job Performance (Check ALL statements which apply)

Endangers others because of carelessness
Does not take care of tools
Is a very slow worker
Does sloppy, inaccurate work

4 minus number checked = score for this item

3. Work Habits (Check ALL statements which apply)

Is late from work without good reason
Is often absent from work
Does not complete jobs without constant encouragement
Leaves work station without permission
Grumbles or gripes about work

5 minus number checked = score for this item

4. Employability (Circle only ONE)

Fully employed - 6 months or more
Has been fully employed for 6 months or more in past
Has worked in sheltered workshop 6 months or more
Never employed/employed less than 6 months

Total Economic Self Sufficiency Score ___ ≤7 = substantial deficit